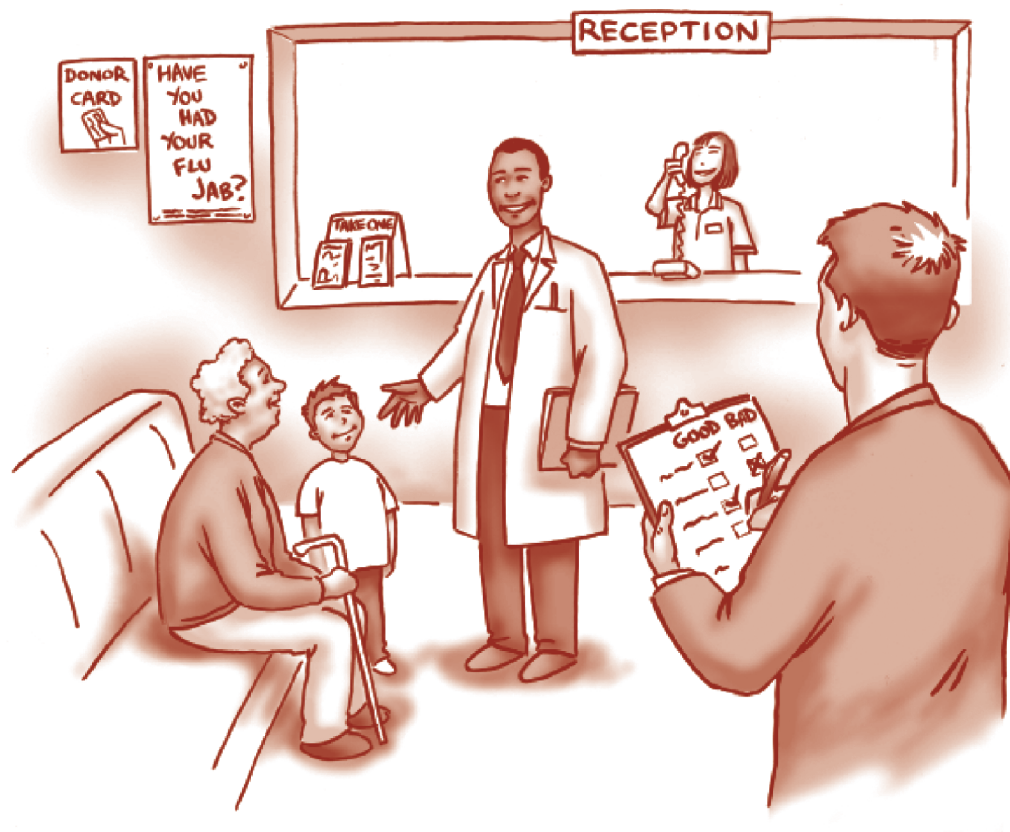


# It's Our Health Service!

## Improving the Health of People with Learning Disabilities

A guide for NHS Services, their partners and advocacy groups



How people with learning disabilities and family carers can be involved in improving the quality of health services.



scottish  
consortium  
for learning  
disability

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**[www.nhshealthquality.org](http://www.nhshealthquality.org)**

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NHS QIS commissioned this guide because of the need to increase the involvement of people with learning disabilities and family carers in assessing service quality. It is anticipated that the guide will be used to improve the quality of services provided, through the continual involvement of service users and carers.

David Steel

In your training we would like to know that YOU will be taught how to help us be more relaxed, to give us reassurance so that we feel 'safe in your hands'. Good Communication and Relating skills are very important.

Sandy Galbraith

The Scottish Consortium for Learning Disability (SCLD) and NHS QIS have together designed this guide which includes a questionnaire specifically for carers, to help guide their input in a consistent and helpful manner. The questionnaire is a valuable tool in giving information to NHS QIS and the NHS Boards on how well, or not so well, the NHS Board is delivering its services to you and the people you care for. As a carer, your health is vitally important too and this should not be forgotten.

Anne Brown

### Introduction

The Scottish Consortium for Learning Disability (SCLD) and NHS Quality Improvement Scotland (NHS QIS) have worked together to produce this guide on involving people with learning disabilities and family carers in improving service quality. People with learning disabilities and family carers worked as consultants with SCLD to say what should be in this guide. The focus of this guide is to help NHS services and partners develop ways to involve and include people with learning disabilities and autistic spectrum disorders (ASD), their carers and family members, in order to improve the quality of services in accordance with the NHS QIS *Quality Indicators ~ Learning Disabilities*, published in February 2004. This involvement will continue in joint inspection processes as they develop.

The aim of the guide is to:

- provide ideas and guidance on how to involve people with learning disabilities and family carers meaningfully in improving service quality and in ongoing internal and external reviews of the quality of all health services
- give examples of materials that can be used to evidence the quality indicators
- provide accessible information about the quality indicators that can be used to inform local groups and engage them in improving the quality of services.

### What NHS Quality Improvement Scotland expects

NHS QIS commissioned this guide because of the need to increase the involvement of people with learning disabilities and family carers in assessing service quality. It is anticipated that the guide will be used to improve the quality of services provided, through the continual involvement of service users and carers.

NHS QIS is involved in a programme of peer review visits to assess performance of the service for people with learning disabilities in relation to the *Quality Indicators~Learning Disabilities*. In this programme of visits NHS QIS will be working with people with learning disabilities and family carers as members of all the review teams. In doing this NHS QIS has underlined the importance attached to understanding and valuing the perspectives of those who receive health services. Their experiences can make a significant contribution to the process of improving all health services.

NHS Boards and partners should be committed to:

- establishing mechanisms for the continued involvement of people with learning disabilities and family carers in assessing the quality of services

- providing feedback on the results of any consultations
- providing evidence that they have sought the views of people with learning disabilities and family carers
- developing the skills of staff and managers so that listening to and involving people with learning disabilities, is an established part of everyday practice.

### Why involvement matters

Involving people with learning disabilities and family carers is an essential part of the NHS QIS *Quality Indicators~Learning Disabilities*. There are sound reasons for this:

- promoting patient and public involvement is a core commitment of NHSScotland
- listening to service users and carers is an effective way to improve service quality – people are the experts about their own experiences
- people with learning disabilities have too often had no say in decisions. Fundamental changes are needed if they are to engage actively with the health service
- there is overwhelming evidence that the health outcomes of people with learning disabilities need to be improved. NHS Boards will only achieve improvements by working in well planned partnerships.

### How this guide can help you

The guide has been prepared to help you engage people with learning disabilities and family carers in the implementation of the quality indicators. It will also assist you to develop involvement in taking forward the outcomes of review visits and in joint inspection programmes.

The guide contains a number of good practice tools including:

- guides to involving people with learning disabilities, family carers and children
- good practice tips
- samples of questionnaires and other ways to collect information
- information about the quality indicators and review process for advocacy groups
- resources and contacts.

These tools and other materials are also available on the accompanying CD to make it easier for you to customise them for your own use. The CD also

contains additional material in the form of video clips which you can use for staff training presentations and in group discussions involving people with learning disabilities and family carers. On the CD you will also find live links to many of the resources (including relevant legislation and contact organisations) listed in Part 5 of this guide. The materials provided in this guide are examples to get you started. You will be the best judge of how to use them. You may want to focus on issues that are priorities for your local service and to use methods and materials that are compatible with your own communication approach.

It is **your** service and this pack is intended as a guide to help you get the most out of the NHS QIS *Quality Indicators ~ Learning Disabilities* and to assist your work to improve NHS services for people with learning disabilities and family carers.

### How this guide is organised

**Part 1 Strategic Framework:** outlines the overall policy framework.

**Part 2 Listening and Learning:** gives guidance on communicating with people with learning disabilities and family carers.

**Part 3 Mapping the Indicators:** maps the quality indicators to show when children and adults with learning disabilities and family carers can best contribute to the quality indicators for people with learning disabilities and family carers

**Part 4 Using Experiences Effectively:** outlines various methods of obtaining information effectively. It gives practical examples and top tips for using experiences effectively. Includes a toolkit which contains sample materials.

**Part 5 Resources:** provides further information including references, contacts, and links to websites and useful leaflets. It includes details of health information specifically for people with learning disabilities and family carers.

### Who is it for?

The information in this guide is for everyone with an interest in the quality of health services for people with learning disabilities. The guide does not comprehensively cover the needs of children and adults with autistic spectrum disorder as it follows the coverage of the NHS QIS *Quality Indicators ~ Learning Disabilities*. Some materials have been prepared specifically for particular target audiences. The person with lead responsibility for the implementation of the NHS QIS *Quality Indicators ~*



## Overview of guide

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*Learning Disabilities* should make sure that all the main stakeholders have copies of the relevant parts of the pack. Wherever possible it is a good idea for relevant organisations and individuals to have copies of the full pack so that they can see the big picture. Relevant audiences include managers and professionals in health services that are not specifically for people with learning disabilities, voluntary organisations and groups of people with learning disabilities or family carers.

### Making the guide better

There are several ways you can help us to make this guide better:

- you can fill out the evaluation form and send it back to us, at the NHS QIS freepost address, so that we can find out what you think
- you can send us good practice examples of things that have worked so we can share these with others.

# Strategic Framework

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## The importance and value of public involvement

Public involvement is a key part of NHS Scotland's commitment to improving health. Our National Health: a Plan for Action, a Plan for Change, (Scottish Executive Health Department [SEHD], 2001) established the aim of involving people and communities in the design and delivery of health services. The Scottish Executive has said that it aims to work

‘with the NHS to ensure that a patient focus is embedded in the culture...and to ensure that listening, understanding and acting on the views of local communities, patients and carers is given the same priority as clinical standards and financial performance.’

The benefits of involving people include:

- awareness of how the service is actually experienced
- a stronger partnership with service users and family carers
- opportunities to improve the service and avoid mistakes.

NHS QIS Patient Focus and Public Involvement Framework (NHS QIS, 2003), was developed in line with the four broad themes outlined in, Patient Focus and Public Involvement (SEHD, 2001). It gives full details of the approach that NHS QIS will take to securing an effective partnership with the public.

The NHS Reform (Scotland) Act 2004 which came into effect on 30 September 2004 creates specific duties to involve the public and create equal opportunities. The next phase of the Patient Focus and Public Involvement agenda will require consideration to be given to the assistance that equalities groups need to contribute to the design, development and delivery of policies and services in order to ensure that the health service engages with the public and responds to the individual needs of patients. The requirement to inform, engage and consult the public in order to develop responsive services is equally the subject of guidance in community care.

This commitment to public involvement is integral to Community Health Partnerships (CHPs) which represent a key driver for the role of patient and public involvement in enhancing the quality of services. The draft advice note on Involving People in Community Health Partnerships sets out the expectation that patients, carers, members of the public, community groups and voluntary organisations should be involved in the development of local Public Partnership Forums (PPFs) (SEHD, 2004). There are other indications of the high priority given to public involvement in improving the quality of public services and the feasibility of doing so. Lay assessors are an established part of the NHS QIS review process and are also currently

the subject of a pilot by the Care Commission. The Department of Health funds and supports Involve, an organisation to promote the involvement of users in health services research.

Children and adults with learning disabilities or Autistic Spectrum Disorder (ASD) and family carers can successfully participate in the public involvement agenda at all levels. The active involvement of people with learning disabilities and/or ASD in decisions that affect their lives and in the development of services was a core principle of the review of services for people with learning disabilities, 'The same as you?' (Scottish Executive, 2000) which established a precedent for a high level of participation which has continued with the involvement of people in national policy implementation through the National Implementation Group for The same as you? (SAYIG) and local Partnership in Practice (PiP) forums.

Groundbreaking developments in Scotland in the public involvement of people with learning disabilities include the appointment by the Mental Welfare Commission of a person with learning disabilities as a part-time commissioner and the commitment of NHS QIS to involve people with learning disabilities and family carers in all the panels for reviews based on the *Quality Indicators ~ Learning Disabilities*. The active involvement of People First (Scotland) and Pamis has made this possible across Scotland. People with learning disabilities and people with ASD as well as family carers are also part of the User and Carer panel which is an integral part of the 21<sup>st</sup> Century Review of Social Work. The Scottish Consortium for Learning Disability (SCLD) engages people with learning disabilities as co-trainers in the delivery of its training programme and has worked with NHS Education for Scotland to implement the recommendations of Promoting Health Supporting Inclusion that all first year student nurses in Scotland should receive training by people with learning disabilities and family carers.

## Continuous quality improvement

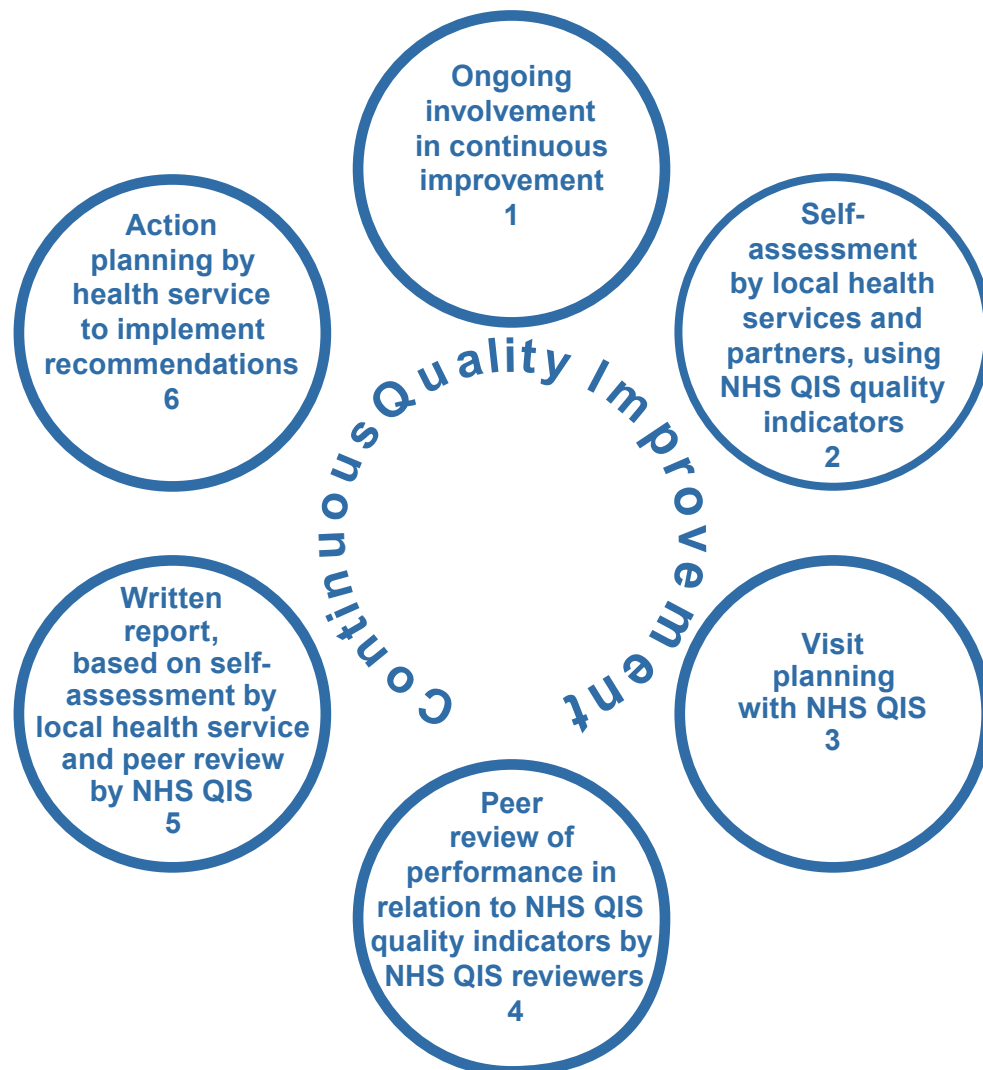
Following the enquiries into the failures to protect four vulnerable adults in Scottish Borders from abuse over an extended period, a process of 'joint inspection' has been initiated to ensure that there is appropriate co-ordination and information sharing between the various inspectorates which are concerned with the quality of services for people with learning disabilities including the Social Work Inspection Agency (SWIA), NHS QIS, the Care Commission, Her Majesty's Inspectorate of Education (HMIE) and Her Majesty's Inspectorate of Constabulary. The NHS QIS *Quality Indicators ~ Learning Disabilities* will provide the framework for the health-related aspects of the joint inspection process.

The revised NHS QIS *Quality Indicators ~ Learning Disabilities* are used by NHS QIS to assess performance in NHS Board areas throughout Scotland.

Each NHS Board is asked to undertake a self-assessment of its service against the quality indicators and contribute to the work of 'joint inspection'. A review team visits the NHS Board on behalf of NHS QIS to follow up this self-assessment exercise with an external peer review of performance in relation to the quality indicators. NHS QIS reports the findings for the NHS Board based on the self-assessment exercise and on the external peer review.

## A cycle of quality monitoring

### Process of an NHS Quality Improvement Scotland review

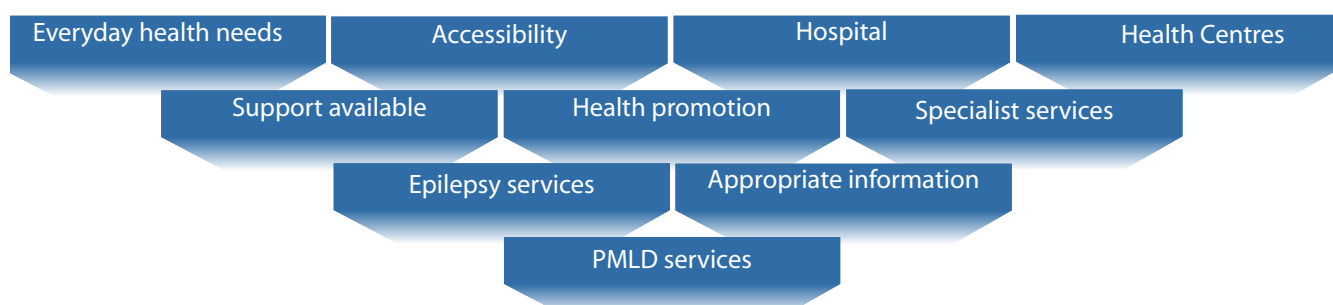


- 1 Involving people with learning disabilities and family carers using a variety of methods. Also involving local authorities and other partner organisations.
- 2 Including views gathered from a range of local people with learning disabilities and/or ASD and family carers.
- 3 The NHS Board liaison co-ordinator will facilitate this.
- 4 Self-assessment matched against evidence gathered during the review.
- 5 Both local reports and national thematic reviews will be published.
- 6 What actions have been taken as a result of the self-assessment by the service and the NHS QIS report?

An NHS QIS review is part of a cycle of quality monitoring designed to enable you to make a continuous improvement in your services. Listening to the views of people with learning disabilities and family carers should not be a one-off exercise for the benefit of the NHS QIS review team. In achieving the criteria set out in the quality indicators it is expected that services will take a strategic approach to the involvement of people with learning disabilities and family carers in standard setting, performance review and audit. The views of people with learning disabilities and family carers are not only relevant to reviews of services for people with learning disabilities. People with learning disabilities use a whole range of health services. Through the implementation of the quality indicators, and the NHS QIS peer review of services for people with learning disabilities, the views of people with learning disabilities and those of family carers are incorporated into all service reviews.

### Service delivery: a tiered approach

People with learning disabilities and their carers will give their views on all aspects of the quality of the health services.



The NHS QIS quality indicators for learning disabilities are consistent with a 'tiered' approach to service planning and delivery, going from general to specialist services.





A strategic approach to the involvement of people with learning disabilities and family carers will entail the identification of lead responsibility, allocation of resources, the identification of key stakeholders and mapping of opportunities to collect information as part of routine care. This work should be linked to the Patient and Public Involvement agenda as well as to Clinical Governance activity and work to implement the Disability Discrimination Act.

The review process operates at different levels. Small improvements can be very worthwhile and it is important to find ways to recognise success and improvements achieved by frontline staff.

## Partnership working

Reducing health inequalities and improving health and wellbeing requires a strategic and collaborative approach across agencies that takes into account the need to ensure that equalities groups have fair access to services and life opportunities. Gathering evidence for the NHS QIS *Quality Indicators ~ Learning Disabilities* will entail relationships with a number of partners including parts of NHS Scotland that do not specialise in the health needs of children and adults with learning disabilities or ASD, local authorities, voluntary sector organisations and people with learning disabilities and family carers both individually and through organised groups. This approach sits well with increasingly integrated approaches to the delivery of services for people with learning disabilities, as well as the development of co-ordination between inspection regimes. This section maps out some of the stakeholders. Materials to inform a variety of stakeholders, but particularly people with learning disabilities and/or ASD and family carers can be found at the end of Part 3 of this Guide.

Community Health Partnerships (CHPs) are the organisations which are responsible for managing a wide range of community based health services and, in dialogue with local authorities, potentially other care services. The aim of CHPs is to improve the way local community health services are organised and managed across Scotland. CHPs build on the work of Local Health Care Co-operatives (LHCCs), but are larger organisations with wider responsibilities and greater influence.

A shared strategic approach is required across the CHPs in each NHS Board area to address the needs of children and adults with learning disabilities and/or ASD. The Scottish Executive has issued statutory guidance for the establishment of CHPs and a number of advice notes. One was specifically related to services for people with learning disability and autistic spectrum disorder. Learning Disability/ASD Partnerships will also provide a focus for strategic engagement with Partnership in Practice (PiP) forums.

PiPs should provide a clear, joint vision of the future direction and funding of services for people with learning disabilities. They set out specifically how local authorities, with their partners, plan to use both existing and new resources over the next 3 years. They should, therefore, focus on measures to enable people with learning disabilities to:

- be included, better understood and supported in their communities
- take part in discussions about their needs, through being better informed
- be at the centre of decision-making
- have the same opportunities as others to get job, develop as individuals, have leisure pursuits, etc
- be able to use local services wherever possible, and special services when they need them.

It is likely that there will be local forums that are already involved in implementing and monitoring the action plans arising from the local PiPs. There will also be local forums for children's planning. It would be useful to build on these to provide support for public engagement and involvement with the NHS QIS review.

Within the NHS there will be people outside child health and learning disability services who will be key contacts. They will include colleagues in mental health and the lead for Patient and Public Involvement, and Health Improvement, and for DDA implementation. Try to identify allies and champions within these other services, including acute health services.

In child health and learning disability services there will be practitioners who will be invaluable in terms of networks and skills in communicating with people with learning disabilities. Start with your community teams, child health teams and community paediatric teams. Make sure you involve your speech and language therapy services.

Many areas now have local area co-ordinators (LACs) who will be in touch with people with learning disabilities and their families, some of whom may not be in touch with other services. LACs are likely to have strong connections with other groups and networks. There is a list of local area co-ordinators and their contact details on the LAC page of the SCLD website –<http://uk.geocities.com/localareacoordination/>

As part of the development of Single Shared Assessment and the eCare initiative there should be work happening locally to promote information sharing and develop a local database of people with learning disabilities. If you do not know who is taking forward this work in your area or you want to know more about the national dataset contact the eSAY team at SCLD.

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## Policy framework

The process of engaging people with learning disabilities and family carers in improving the quality of health services is part of the broader strategic framework in Scotland. The principles of social justice, equality and diversity, anti-discriminatory practice and customer focused services are common to many elements of this strategic framework. Key legislation includes:

- Disability Discrimination Act 1995
- Human Rights Act 1998
- Adults with Incapacity Scotland Act 2000
- Race Relations (Amendment) Act 2000
- Regulation of Care (Scotland) Act 2001
- Community Care Health (Scotland) Act 2002
- Freedom of Information (Scotland) Act 2002
- Mental Health (Care and Treatment) (Scotland) Act 2003

Key policies include:

- 21<sup>st</sup> Century Social Work Review.
- Carers Strategy
- Closing the Opportunity Gap
- For Scotland's Children
- Health Improvement Strategy
- Joint Future
- Modernising Government
- Patient Focus and Public Involvement
- Scottish Executive Equality Strategy - The Wider Challenge
- Social Justice A Scotland Where Everyone Matters
- The Partnership Agreement

In the Resource section of this guide (Part 5) you will find information on relevant legislation, policy statements and reports and useful organisations.

Within this framework there are many common drivers for increasing participation, reducing inequalities and making services more responsive to the needs of individuals, taking into account the diverse needs of the population in Scotland.

The Equality and Diversity Impact Assessment Toolkit provides a mechanism for NHSScotland to 'ensure that a commitment to equality of opportunity and anti-discriminatory policies become part of our day-to-day work within the wider Community Planning context'.

The equality and diversity agenda addresses equal opportunities as defined in Schedule 5 of the Scotland Act 1998: ‘the prevention, elimination or regulation of discrimination between persons on the grounds of sex or marital status, on racial grounds or on grounds of disability, age, sexual orientation, language or social origin or of other personal attributes including beliefs or opinions such as religious beliefs or political beliefs’. Partnership for Care committed the Scottish Health Department to extend the principles of Fair for All to ensure that ‘our health services recognise and respond sensitively to the individual needs, background and circumstances of people’s lives’. The Scottish Executive’s Mainstreaming Equality website demonstrates how equality can provide an overarching framework for work with equality target groups which include people with disabilities.

Strategies and policies specific to children and adults with learning disabilities and/or ASD are also based in the same principles of rights, respect and citizenship. These are summarised at the beginning of the Learning Disability Health Needs Assessment Report:

“People with learning disabilities and/or ASD are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community of which they are a full part.”

The same as you? set out seven principles for services and supports for people with learning disabilities. These are reflected throughout the NHS QIS Quality Indicators ~ Learning Disabilities and are that people with learning disabilities should be:

- valued
- treated as individuals
- asked about what they need and involved in choices
- given the help and support to do what they want to do
- enabled to access local services, like everyone else
- enabled to access specialist services when they need them
- enabled to have services which take account of their age, ability and needs.

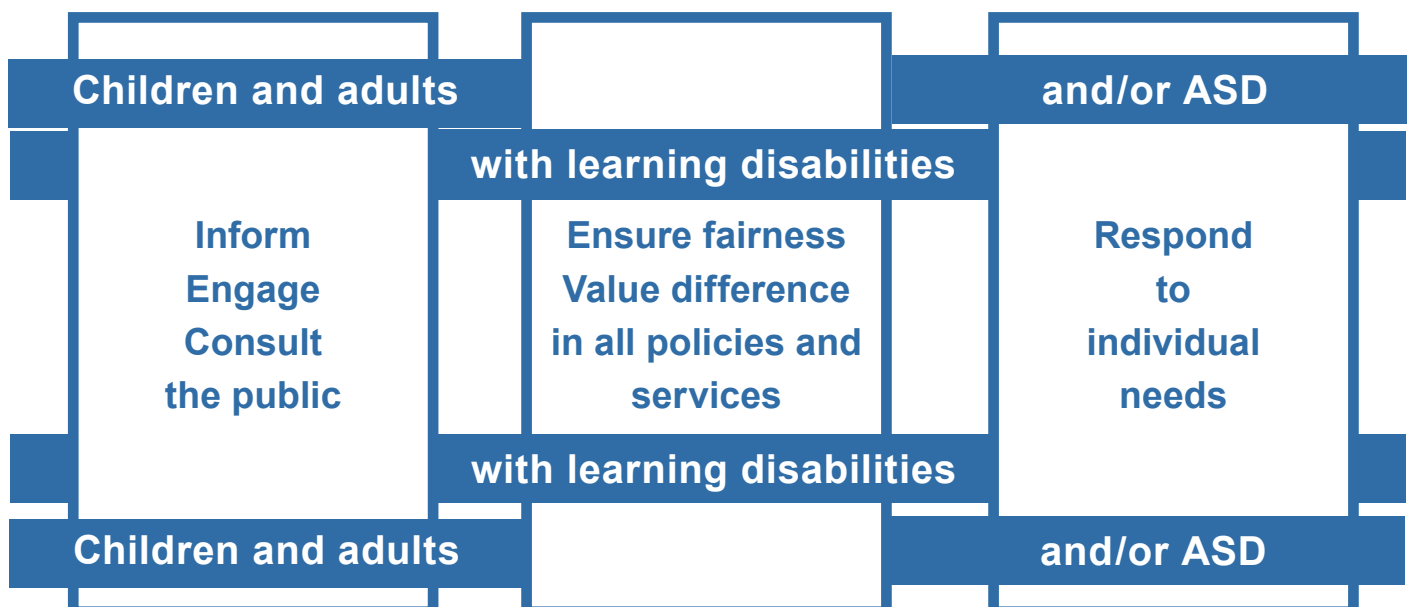
These principles are reflected in range of policies and reports specific to children and adults with learning disabilities and/or ASD which can inform the application of the NHS QIS Quality Indicators ~ Learning Disabilities. The most important of these are:

- Adults with Incapacity (Scotland) Act 2000
- The same as you?

- Promoting Health Supporting Inclusion
- The Learning Disability Health Needs Assessment Report
- Autistic Spectrum Disorder Needs Assessment.

In summary, there are strong drivers to make health services responsive to the needs of children and adults with learning disabilities and/or ASD. These are evidence-based and in harmony with the overall equality and diversity strategies of NHS Scotland and its partners.

### Key drivers for public involvement





# Listening and Learning

Part 2

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## Involving people

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### Introduction

As the title of Part 2 suggests, the effective engagement of children and adults with learning disabilities and/or ASD and their family carers depends on a willingness to respect what they know and to make changes that take account of their experiences. In 'Listening and Learning' we focus on some of the practical arrangements and practices that will help to make this involvement effective. Part 2 is in three sections:

- A brief note about the process of involving people with a focus on what should happen before and after a consultation such as an NHS QIS review. This will be especially useful for anyone who has responsibility for organising the process.
- A introductory briefing note on communicating with children and adults with learning disabilities prepared by Sally Millar of the CALL Centre. This could be used as introductory material with staff who may be collecting evidence for the NHS QIS *Quality Indicators ~ Learning Disabilities*.
- Top Tips for involving people with learning disabilities, children and family carers. These are intended for anyone involved in making arrangements.

In Part 3 of this guide you will find materials to help you publicise an NHS QIS Review in the way recommended here.

The references referred to in Sally Millar's briefing will be found in Part 5 (Resources).

### Getting people involved

SCLD brought together some people with learning disabilities and family carers to help prepare this guide. They stressed that there would be many groups and individuals locally who could help the NHS find out the views of people with learning disabilities and family carers. However, for them to do this effectively they would need:

- information in a form that could be used
- plenty of time to prepare people
- access to independent support.

A communications strategy will be essential to the success of any consultation. One of the first priorities should be to try and put together the most up-to-date list of local advocacy groups, provider organisations, individuals and family carers and to get out to them the message that a review will be happening and that you are interested in having their views.

## Involving people

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It is also important that NHS and social care staff working in local authority services and those provided by the independent sector have access to the same information so that they feel prepared to tell people what is happening. This approach will also be relevant to joint inspection.

It is impossible to overestimate the amount of notice that is helpful for local groups to be able to respond to requests for information. This is not to say that advocacy and other groups are unduly bureaucratic. On the contrary they can often respond extremely rapidly and efficiently to a targeted request, provided that the preparation has been done to explain what is needed and why. We have, therefore, provided sample information that can be used or adapted to tell people about the review so that they are ready when you send out specific requests. You may want to put posters in your services to remind staff as well as users of the service that views are wanted. Or you might design a simple reminder that people could be given when they attend an appointment – like a bookmark, for example.

### Feedback during and after a review

Involving people is a two-way process as well as a continuous one. It is very important that you agree a budget and allocate time to ensure that people will be kept informed about what is happening and that you make the findings of the report available in an accessible way. Your local speech and language service may be able to advise you. Drama is a good way to get messages across and you may have a local college class that might be interested in putting a scenario together.

But it is not enough to publicise the report. People will want to know what is being done to change things for the better and whether this is working. This is where a strategic approach will bring rewards as you can draw on the networks you have worked with before and during the review to set up continuing channels of communication with people with learning disabilities and their families, advocacy, support groups and local services to inform them of progress and involve them in continuing to monitor quality.

## Frequently asked questions

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### How much time should we allow to organise a consultation?

Imagine that you are the development worker for a local advocacy group. You have a monthly meeting. People help to plan the agenda well in advance so that everyone knows the topics that are coming up. In order to make sure that everyone can take part you make sure that all information is accessible and you send this out at least 2 weeks before a meeting so that people have time to prepare with their supporters. To cover a topic well it is usually a good idea to revisit it over several meetings. So if you wanted to get a meaningful response back to a consultation by the end of September you would want to know about it by the beginning of June!

A big factor that will influence your planning is whether you already have the contacts to get in touch with people with learning disabilities and their families or whether you are having to build those networks.

### How many people should we consult?

This depends on what you are trying to do. For an exercise that is about improving quality, a purposive sample that represents the different groups of people who use your service is probably the most relevant. You need to ensure that you gather opinions from people in a range of services, circumstances and settings so that you get a rounded picture of your service. It is better to spend time doing a single case study of a family with profound and multiple learning disabilities than to do more interviews but not have any experiences from someone in this situation.

### Where can I find out more ?

This guide provides Top Tips for communicating with people with learning disabilities and family carers. In the Resource section (Part 5) you will find information on other general guides which contain some excellent advice.

## Communication

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### **An introductory briefing**

by Sally Millar from the Communication Aids for Language and Learning (CALL) Centre



The ability to understand and communicate with others is one of the most important of all human functions and skills. Many children and adults with learning difficulties, sensory and/or physical impairments or autistic-spectrum disorders also have speech, language, communication and interaction difficulties. This means that even if they are physically present at a review, interview or consultation, they may be excluded from discussions and may be unable to express their views effectively. People with communication difficulties are often overlooked or ‘talked over’ by more able speakers in group activities and discussions. People with severe communication difficulties are commonly not consulted at all about their interests, preferences, choices and opinions.

### **Just because I can’t speak doesn’t mean I have nothing to say!**

Everybody communicates in some way or another, perhaps just through their reactions and behaviour, but we don’t always have time to get to know them properly and to ‘learn their language’. It is our responsibility to show that we have tried to understand their particular communication channels and methods and to collect information about their views by whatever routes may be feasible. Even when time is limited, we should be able to record *something* about how a person expresses him or herself, and what they like and don’t like, rather than simply writing them off as ‘unable to speak’. The challenge is - how do we do this? Successful communication may depend on how effective we are as facilitators and listeners, rather than on the person with the communication difficulties.

### **Key approaches to communication**

- Prepare in advance
- Find out a bit about what level and type(s) of communication disability you will be dealing with.
- Identify key contacts who will be communication support people, meet or at least talk with them in advance if possible to discuss and plan communication approaches, and try to ensure they will also be on hand at the time of your visit. If a deaf sign interpreter is necessary, remember they have to be booked well in advance.
- Plan to allow extra time for reviews involving people with particular difficulties with communication.

## Communication

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- Make sure the person has been informed of and prepared for your visit, and has agreed to be involved/interviewed. Send a pictorial or symbol letter or 'social story'-style guidance sheet (Aitken & Millar 2004).
- Collect and read any documentation about how a particular person communicates, eg a personal communication passport (Millar & Aitken, 2003 – passports training is also available from the CALL Centre), along with any other relevant information, eg about their vision or hearing.
- Try and learn about basic interactive non-verbal communication techniques by observing a speech and language therapist or other specialist, eg waiting in silence, expectant looking, alternating eye gaze.
- Be aware of any special communication techniques or aids used by the person, eg gesture or signing, low or high tech communication aid (Communication Matters see Useful organisations Part 5). If any are used, make sure these are available when the review takes place; otherwise it's like asking someone to watch a film without their glasses or sit an exam without a pen! Make sure you know which hand or finger he or she prefers to use for holding things, pointing etc.
- Plan to use a range of different techniques (Aitken & Millar, 2002, 2004; Marchant et al 1999; Murphy et al, 2002) and pack all the necessary materials, ready for instant deployment. Remember that many people have concentration difficulties and you may be able to engage their attention only for short bursts.
- Be prepared to use plenty of relevant pictures, photos (or the means to take and view or quickly print them out on the spot), and/or symbols, as most people benefit from information presented visually. Questions that are written or purely oral will not usually be appropriate.
- Try to use a digital camera or video to record a person's non-verbal reactions and responses and to record the tangible, visual outcome of any practical activities carried out (eg poster, mind map, Talking Mats™, diary or 'survey/voting session') created in the course of the review.

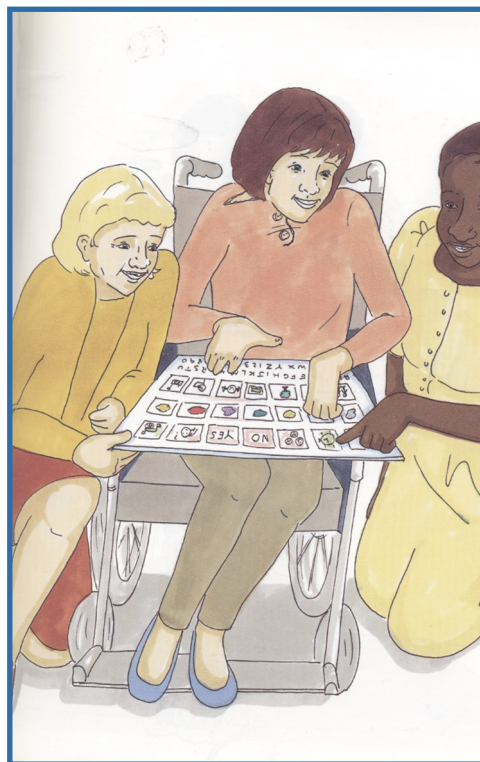
## Communication

### Special communication techniques

Unaided communication includes facial expression, gaze, eye-pointing, speech attempts and any vocalisations, body language, movements, gestures and signs.

Low tech communication aids are usually laminated paper charts or booklets with pictures and symbols arranged in topics, that the person can point to, to make choices and express him/herself.

High tech communication aids (which need at least a battery to operate) are devices with stored words and messages. The simplest kind of voice output communication aid (VOCA) has just one recorded message activated by pressing it; some have about 8-32 stored messages; the most complicated and powerful VOCAs (specialised computers) can store hundreds and thousands of vocabulary items, across many locations, in different 'layers' or linked screens.





## Communication

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### Interview hints and tips

- Where communication difficulties are severe, using a ‘proxy’ or ‘communication facilitator’ (ie someone who knows the person very well and can interpret the person’s reactions and communication efforts) is a valuable source of information, but it’s better if this can be supported by further evidence. At the very least, ask two or three people (separately) for their interpretations, not just one; question, discuss and cross-check differing reports and interpretations.
- Try to observe and interact with the person yourself, but do this in a familiar setting, with another person present that he/she knows and trusts.
- Keep your own language short and simple, and use visual clues as much as possible.
- Use checklists to keep track of any communicative signals that you are told about or pick up (CALL Centre Communication Behaviour Checklist 1).
- Find out and note down exactly how the person signals ‘yes’, ‘no’ and other key meanings (CALL Centre Communication Behaviour Checklist 2).
- Use your eyes as well as your ears to pick up what the person’s response means, if their spoken message is unclear.
- Only ask one question at a time and leave time for the person to respond.
- Use closed ‘yes/no’ questions, if you have to, for speed – but be suspicious of rapid ‘yes’ ‘yes’ ‘yes’ responses – this often means the person hasn’t understood the question properly, or just wants to please you, is scared to risk causing trouble, or hasn’t engaged in the process fully. Include some questions that need a ‘no’ answer to test that the person is following and responding appropriately.
- Also try to use ‘open’ questions like “What do you like to do at night?” rather than all closed questions, “Do you like watching TV?”. Specific questions might work better than abstract questions, eg “What did you do last night?”.
- Ideally, leave time for the person to start or change the topic and share control of the conversation, instead of always just responding to you.
- Find out about specific interview techniques such as Talking Mats™ (Murphy 1997, 2002). Talking Mats™ training is also available from the Augmentative and Alternative Communication (AAC) Research Unit, Stirling University.
- Relax and enjoy the communication – this will not be as scary as it sounds and you will probably find the whole experience very illuminating!



## Communication

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### Key contacts

- The most important contacts are obviously the people who know the person best and who spend the most time with the person. This is not necessarily the most senior person in an establishment! Links between key contacts from home and family, school, short breaks and respite care setting(s), day placement, residential care will need to be explored – communication and behaviour can be different in different settings and those differences may provide valuable clues about the things that are most important to someone.
- The local Speech and Language Therapy (S&LT) service will be able to provide background on some individuals' communication, and also general information and advice, and perhaps practical support, on different communication techniques in use in specific settings.
- In many cases, S&LTs may be prepared to provide training on different communication techniques.
- In Scotland, there are a number of specialised centres and services that provide advice and information on special communication methods, low and high tech, and in some cases assessment and loans of communication aids for trial, and training. See Resources (Part 5).

Communication

CALL Centre Checklist

CALL Centre Communication Behaviour Checklist 1				
Date: <small>write in new date in 'child/adult does' section when new behaviour is added</small>				
_____ does	in this setting	People think it means	This is the best way for people to respond	The probable result will be

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## Communication

### CALL Centre Checklist

<b>CALL Centre Communication Behaviour: Checklist 2</b>	
<b>Key Communication Issues</b>	<b>Your Observations (what you see, hear): to be discussed and agreed (leave blank or write 'Don't Know' if you can't agree, to show gaps for further investigation)</b>
1. How do you know s/he is relaxed, at ease, comfortable?	
2. How do you know s/he is happy, or enjoying something?	
3. How do you know s/he wants something or likes something (a particular object or activity)?	
4. How do you know s/he is really excited?	
5. How do you know s/he is not at ease, is uncomfortable?	
6. How do you now s/he is unhappy, or not enjoying something?	
7. How do you know s/he doesn't like / want something (rejection of a particular object or activity)?	
8. How do you know s/he is really distressed or in pain?	
9. How does s/he attract & gain your attention when you are not paying her any attention?	
10. How does s/he generally make herself understood (eg. pulling you, vocalising, gestures, pointing, reaching etc.)?	
11. How do you know if s/he is communicating?	
12. How do you communicate with her?	
13. What kinds of information can s/he get across to you?	
14. Does s/he indicate preferences / make choices? How?	
15. If you offer a list of options, how does s/he signal to indicate her selection?	

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## Listening to people with learning disabilities

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### Top Tips for consulting people

- 1 As soon as possible tell all the advocacy organisations, provider organisations, day services, carer groups and others about the consultation, for example an external review such as NHS QIS. Write to individuals and families. Give them accessible information that is easy to understand about the review so that they have time to prepare. There are samples in Part 3.
- 2 Offer different ways for people to give their views:
  - open days
  - telling their story
  - free phone line
  - form to fill in
  - come to a group
  - speak to someone or telephone.
- 3 Give people information as well as asking for it, eg at an open day. (Some useful resources are listed in Resources Part 5 of this guide)
- 4 Ensure people have the support they need to take part. This may include support to fill in forms.
- 5 Enable people to have access to independent support so that they feel free to speak out.
- 6 People should be able to speak without staff being present. Encourage them to pick a person that they trust to ask them about the services they receive.
- 7 Make arrangements for transport, communication and changing facilities for children and adults if you are holding an event.
- 8 Speak to your speech and language services for advice about communication, and to advocacy organisations and the patient and public involvement officer to find the best ways to contact people.
- 9 Make it accessible – use symbols, pictures, tape and video.
- 10 Allow the time that is required.
- 11 Explain how you are going to change things
- 12 Appoint a named person so everyone knows who to contact for information.

## Listening to people with learning disabilities

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- 13 Make sure you organise meetings and appointments at suitable times (eg 11am. Do not make appointments really early in the morning).
- 14 Don't exclude people with very high support needs or communication difficulties - there are ways they can be supported to express their wishes, likes and dislikes.
- 15 All people are different. Find out what the person's communication needs are and how best to support them.
- 16 Respect the person's privacy and right to give or withhold consent.

## Listening to children

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### Top Tips for consulting children

- 1 Offer children a range of ways to express their views. These can include:
  - board games
  - drawing or other art work
  - 'posting' a message
  - story telling
  - 'Big Brother' chair or video box
- 2 Don't exclude children with very high support needs or communication difficulties - there are ways they can be supported to express their wishes, likes and dislikes.
- 3 All children are different. Find out what the child's communication needs are and how best to support them.
- 4 A communication passport can help others to know best how to communicate with a particular child.
- 5 Respect the child's privacy and right to give or withhold consent.
- 6 Encourage children to pick a person they trust who can ask them about the service they receive. They should be able to speak without staff being present.
- 7 Organise practical activities - something to do, such as making signs or posters.
- 8 Speak about the child's real life and situations that matter to them.
- 9 Make sure you respond to and follow up concerns and suggestions.
- 10 Make it fun!

## Listening to family carers

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### Top Tips for consulting family carers

- 1 Trust families and work with them – they are a source of knowledge, expertise and continuing support. Also listen to what the child or adult with learning disabilities has to say.
- 2 Listen to the suggestions and wishes of the parents of children with learning disabilities and also to family carers who continue to care or to have responsibilities – they are key partners.
- 3 Consider the health needs of family carers in their own right.
- 4 Provide services that will support the capacity of families to care - especially the families of children and adults with profound and multiple disabilities, eg short breaks, access to specialist services and advice and a named liaison nurse. You will find the service improves for everyone.
- 5 Ensure the provision of appropriate information about health and services to family carers. This should be offered at the first point of contact with a service.
- 6 Provide family carers with opportunities for practical training, eg moving and handling.
- 7 Respect family carers as a valued source of advice about the service, eg in strategic planning and staff training.
- 8 When organising assessment, review or planning meetings consider what might otherwise prevent family carers from attending – times, support, transport, lack of alternative care arrangements.
- 9 Offer different ways for family carers to offer their views on the service, eg a free phone line.
- 10 Make sure that staff receive carer awareness training.

# Mapping the Indicators



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## Introduction

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The focus of Part 3 of this guide is on information. It provides several tools to help all those with an interest to find their way around the NHS quality indicators. It also contains material that can be distributed directly to people with learning disabilities and/or ASD and family carers and to local groups to explain the NHS QIS *Quality Indicators ~ Learning Disabilities*.

The NHS quality indicators chart (on page 2) provides an overview of the quality indicators. All this information should help the service to answer the overarching question:

*‘How well is your health service meeting people’s needs?’*

**Making it real** provides an overview of the content of the indicators and highlights the sections that will need the information you collected about the experiences of people with learning disabilities and family carers.

The **example** - analyses one indicator criterion in more detail.

**Collecting and reviewing the evidence** recommends a variety of approaches to obtaining evidence for the indicators.

The section on **planning an information strategy** gives an example of how data could be obtained across the services and settings where people with learning disabilities could be contacted.

**The Index** will help you to locate specific topics in the indicators.

The **Letter to advocacy groups and others** is for you to send out as early as possible to publicise the review.

The **Guide to the indicators for people with learning disabilities** should be used with people with learning disabilities or the groups who support them. It explains what each indicator says the user of services can expect and it complements the easy-read introduction to the NHS QIS *Quality Indicators ~ Learning Disabilities* ‘Improving the Health of People with Learning Disabilities’. The guide should be used to introduce the key questions for people with learning disabilities included in the Toolkit.

The **Guide for parents and family carers** should be distributed to family carers. It explains to family carers what the indicators say is expected of health services and that their views should be taken into account. It should be used to prepare people to receive the family carer questionnaire included in the Toolkit

## The NHS quality indicators

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## Making it real

This section highlights those parts of the quality indicators where it will be necessary to find out about the experiences of children and adults with learning disabilities and family carers. Criteria that will benefit from evidence of people's experiences are indicated by **I** in the margin. This is not an exclusive list. You will want to examine the individual criteria as there are many places where experiences could contribute.

**GROUP DISCUSSION, INTERVIEW, CASE STUDY, ETC** indicates that there is a sample questionnaire or other approach provided in the Toolkit.

## Mapping the indicators for the effective use of experiences

- 1 **Involvement of children and adults with learning disabilities and their family carers through self-representation and independent advocacy**
  - I** 1.1 effective support for involvement in planning and delivery (**GROUP DISCUSSION**)
  - I** 1.2 involvement in the planning and review of their care across all health services
  - 1.3 accessible policy on access to health records
  - I** 1.4 accessible policies and procedures in place for complaints, freedom of expression, recording suggestions and assessing satisfaction
  - 1.5 strategy for the range of advocacy services
  - I** 1.6 advocacy services promoted through training and access to information and services
- 2 **Promoting inclusion and wellbeing (**GUIDANCE**)**
  - 2.1 staff familiar with Disability Discrimination Act (DDA)
  - 2.2 up-to-date strategy for disability awareness and disability equality training
  - I** 2.3 safe access to health service settings
  - I** 2.4 patient transport services take account of the needs of children and adults with learning disabilities
  - I** 2.5 agreed policy on health improvement and wellbeing takes account of the needs of children (**ACTIVITIES FOR CHILDREN**) and adults with learning disabilities and addresses health inequalities
  - I** 2.6 accessible information on the range of health services available (**FOCUS GROUP**)
  - I** 2.7 services culturally sensitive and respond to the needs of black and ethnic minority children, adults and family carers
  - 2.8 health services support people with learning disabilities to use direct payments

## Making it real

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### 3 Meeting general healthcare needs

- 3.1 up-to-date multidisciplinary care plan for children and adults
- 3.2** assessment of health and capacity of family carers is considered and linked to assessment of users' need
- 3.3 named specialist practitioner linked to each primary care team
- 3.4** primary care services are responsive to the needs of children and adults with learning disabilities and their family carers ([STORIES](#))
- 3.5 children, young people and adults with learning disabilities are included and supported to participate in national screening programmes
- 3.6 specific health needs are assessed and monitored
- 3.7 there is an agreed approach to joint working with social work and other agencies
- 3.8 appropriate health and social care intervention for older people with a learning disability
- 3.9 wheelchair and seating services provided
- 3.10 programme of education about rights and needs for healthcare professionals in all settings
- 3.11 paediatric and general hospital services can get help and support from specialist learning disabilities staff
- 3.12 general hospital services and paediatric hospitals/units aware of and meet needs of children and adults with learning disabilities
- 3.13 palliative care services take account of their needs
- 3.14 clinical guidelines followed and take account of their needs

### 4 Meeting complex healthcare needs

- 4.1 functions of specialised and general health services integrated
- 4.2** continuity of healthcare and liaison through transitions from preschool to school, primary to secondary education, youth to adult services and adult to older people's services
- 4.3 continuity of healthcare between services, eg community, respite, hospital, locality
- 4.4 access to specialist multidisciplinary community services for children
- 4.5 access to specialist multidisciplinary community services for adults
- 4.6 services provided for children and adults with complex needs across the area
- 4.7 community-based services for children and adults with challenging behaviour
- 4.8 evidence-based approaches to management and treatment of challenging behaviour
- 4.9 services for people with learning disabilities with offending behaviour
- 4.10 mental health needs of children and adults with learning disabilities are met in the most appropriate setting
- 4.11 assessment and treatment needs of adults and children with learning

## Making it real

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- disabilities and Autistic Spectrum Disorder (ASD) met according to national guidelines
- 4.12 appropriate range of services to meet needs of people with dementia
- 4.13** appropriate range of services to meet needs of children and adults with profound and multiple impairment and their family carers
- 4.14 services available for children and adults with learning disabilities who have epilepsy

### 5 Inpatient services – daily life

- 5.1 environment managed to reduce hazards and ensure safety
- 5.2 patient accommodation suitable and meets care home standards
- 5.3 privacy and property respected
- 5.4** individuals needs, choice, privacy and dignity respected ([INTERVIEW](#))
- 5.5** people supported to make choices and decisions about daily life and how they spend their time

### 6 Planning services and partnership working

- 6.1** health improvement strategies take needs of children and adults with learning disabilities and family carers into account ([CASE STUDY](#))
- 6.2 measures to address health inequalities in line with Health Needs Assessment report
- 6.3 electronic information on needs recorded (eCare)
- 6.4** healthcare plans for children and adults with a learning disability used in the PiP (Partnership in Planning Agreement) and other strategies
- 6.5 attention to workforce planning and the training and education needs of staff
- 6.6 Community Health Partnerships plan for the needs of children and adults with a learning disability
- 6.7 NHS Board has plans to develop services for children and adults with complex needs
- 6.8 NHS Boards use best quality information about what will make a difference when commissioning health services
- 6.9 agreed plan on hospital closure and developing services in the community
- 6.10 joint arrangements for learning disability services
- 6.11 joint approach to services evaluation
- 6.12 there is a multidisciplinary group for the protection of vulnerable adults
- 6.13 there is a multidisciplinary group for the implementation of child protection policies

## An example

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**“There are opportunities for children and adults with learning disabilities to participate in activities which promote inclusion, social capacity and a healthy lifestyle.”**

*(Quality Indicator 2, Criterion 2.5.6)*

This is an example of a criterion for which you might find it particularly helpful to include some views from people themselves. This example considers children.

### Rationale for information collection

Places to go, people to do things with and activities that make you feel good are essential to everyone's health. They matter just as much to children with learning disabilities yet they may face barriers to joining in even ordinary things. For example it may be harder for them to make friends unless they can go on school trips, use the same transport as their peers and hang out with their friends in the evening.

This is why this indicator focuses on 'opportunities'. It wants to know what is being done to make sure that these everyday opportunities are available to children with learning disabilities. It also identifies the differences which such participation might make to the life of a child with learning disabilities. You may like to think of these as the outcomes of the opportunities that you identify:

- **Inclusion** - do children with learning disabilities have access to opportunities that enable them to belong, to feel part of a group of children of their own age (or do they lead to them being stigmatised or segregated)?
- **Social capacity** - do children with learning disabilities have access to opportunities to enable them to develop the skills and experience of engaging with other people (or do they strip them of opportunities to develop social skills in their own way)?
- **Healthy lifestyles** - do children with learning disabilities have access to information that is suitable for them about how to live healthy lives and do they have the same opportunities as other children to look after themselves, eat well, stay active and safe, try out new things and do things that make them feel good (or do they experience restrictions in access to, for example, leisure activities that make it harder for them to lead healthy lives)?

While children are in the care of health services, for example in hospital or in a short breaks service, it is particularly important that these health needs are remembered.



## An example

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There are many ways that you could seek to obtain children's views on these issues. See the 'Listening to Children' in Part 2 of this guide.

To get some help you could:

- approach a children's advocate or children's advocacy project
- ask for the co-operation of some local schools, after-school care services or the Girl Guides or Brownies
- work with a local short breaks service for children
- ask one of your children's health services to do an activity with some of the children using the service.

The Toolkit includes two tools for seeking the views of children on these issues - the Healthy tree game and the 'I do stuff' exercise.

## Collecting and reviewing the evidence

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The indicators ask for different types of evidence including:

- appropriate strategies, plans and policies
- systems to implement these
- whether good practice is evident across settings
- staff awareness of requirements and good practice
- experiences of children, adults and family carers.

A cycle of continuous improvement might include a variety of approaches to examining these, for example:

- a quality review group examining the appropriateness of policies and what changes or improvements have been made in the service over the past year (this can include people who use services and family carers)
- critical incident technique to examine the effectiveness of systems – this is where a manager, practitioner or researcher goes into a service setting and asks to be told about an actual situation (positive or negative). These accounts are then reviewed to see what can be learned about how systems are actually operating.
- case studies of service quality in different settings – these could form part of student training and placements within the service
- audit of staff awareness of critical quality indicators built into training, evaluation and supervision
- random sample of users of a particular service or carers to measure experiences against specific quality indicators
- gathering and discussion of stories/accounts as basis for improvement
- group discussions of experiences and suggestions for improvement.

Children and adults with learning disabilities and their family carers are the experts about how it feels to use a service. It can be highly instructive for managers and staff to hear directly from them about their experiences. Don't leave this opportunity for the review team only! Opportunities should be taken for staff to listen to focus groups, hear from people with learning disabilities and family carers in staff training and engage individuals and groups in planning, developing and evaluating services.

Local advocacy and carer groups will also be able to contribute actively to identifying problems in the way services operate and to recommending improvements. They should be included as active partners in the quality review process.

The Indicator Toolkit in Part 4 of this guide gives a range of examples of how to gather and use the experiences of people with learning disabilities and family carers.

## Planning an information strategy

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To make the best use of resources it is important to consider the different types of information required for the indicators in the context of local services.

Finding out about the population of people with learning disabilities in your area, the settings they live in and the range of services they access will be time well spent to develop an effective information strategy. The development of a database (see Quality Indicator 6) will help provide systematic information. Meanwhile it is useful to find out:

- the main providers of services locally. These will be known to service commissioners in the council and the board. There may be a local providers' forum.
- the local advocacy, self advocacy and carers' groups.
- what other service reviews are taking place across the various settings – education, social work, children's services, education. All areas have prepared Partnership in Practice Agreements for 2005-2007. This will almost certainly contain information about relevant needs.

An example:

Mairi was given the job of seeing how the available data on health service use could be enhanced to provide information for the NHS QIS review.

First she mapped the various local services against the quality indicators and found out what information was already being collected that could be used. Then she identified a sample of situations in which specific approaches could be introduced to ensure that the views of people with learning disabilities were obtained eg a questionnaire administered by job coaches for people in employment.

Next she spoke to the learning disability services to identify where the people with learning disabilities could be reached. These could include day services, advocacy groups and supported living providers. She set up a system of enquiries, building on work already happening where possible, to obtain the views of a wide range of people with learning disabilities and family carers.

To help her she made use of local resources including the patient and public involvement lead and the speech and language service. She found that there were several groups ready to help her including a local self advocacy group, a parent group, members of the local providers' forum and a health sub-group set up through the Partnership in Practice Agreement (PiP).

Then she checked out with her informants if there were any groups of people with learning disabilities she was likely to have missed out. She was told that very few families from black and minority ethnic communities were in touch with learning disability services locally. So she spoke to the service commissioner in the local authority about jointly funding a piece of development work. They decided to start with speaking to the healthy living centre which had an Asian women's health group.

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All Criteria	Specific Criteria
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1.4	
	1.5.2
	1.6.5
2.3	
	2.4.2
2.6	
	3.3.1
	3.12.2
	4.1.2
	4.2.8
4.4	
4.5	
	4.11.1
	4.12.1
	4.13.5
	4.14.1
	5.3.1
	5.3.4
	5.3.8
	5.4.7
	6.2.2
	6.4.2

### Accommodation

All Criteria	Specific Criteria
5.1	
5.2	
5.3	
5.4	

### Adaptations & Equipment

All Criteria	Specific Criteria
	2.3.4
	2.3.5
	3.1.7
	3.7.4
3.9	
	4.3.4
	4.13.4
	5.2.3
	5.2.8

### Additional Needs

All Criteria	Specific Criteria
2.2	
3.1	
3.6	
3.8	
4.1	
4.6	
6.7	

### Admission

All Criteria	Specific Criteria
	4.9.4
	4.10.2

### Adults with Incapacity (Scotland) Act 2000

All Criteria	Specific Criteria
	3.1.2
	3.5.1
	3.10.2
	4.2.7
	5.5.6

### Advocacy

All Criteria	Specific Criteria
1.2	
	1.3.2
	1.4.2
1.5	
1.6	
	3.1.5

### Appropriate Adult

All Criteria	Specific Criteria
	6.12.3

### Assessments and Care Plans

All Criteria	Specific Criteria
	1.2.2
	2.8.2
3.1	
3.2	
	3.6.1
	3.6.4
	3.7.1
	3.9.3
4.1	
	4.2.5
	4.2.6
	4.2.7
	4.4.8
	4.5.1
	4.5.5
	4.6.2
4.7	
	4.8.4
	4.8.5
	4.9.5
	4.10.5
	4.10.6
4.11	
	4.12.1
	4.13.1
	4.14.1
	4.14.2
	5.3.6
	5.5.1
	5.5.9
	6.3.3
	6.9.2

### Audiology

All Criteria	Specific Criteria
	3.1.4

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## Autistic Spectrum Disorder (ASD)

All Criteria	Specific Criteria
	1.5.6
2.2	
	4.6.2
4.11	
	5.4.3

## Black & Ethnic Minority

All Criteria	Specific Criteria
	1.1.5
2.7	
	5.5.9

## Care Programme Approach

All Criteria	Specific Criteria
	4.10.6

## Challenging Behaviour

All Criteria	Specific Criteria
	4.6.2
4.7	
4.8	
	5.4.3

## Child & Adolescent Mental Health Services

All Criteria	Specific Criteria
	4.10.3
	4.10.7
	6.4.4

## Child Protection

All Criteria	Specific Criteria
	6.13.1

## Children

All Criteria	Specific Criteria
1.1	
1.2	
1.3	
1.4	
1.5	
	1.6.3
	1.6.6
	1.6.7
2.1	
2.2	
2.3	
2.4	
2.5	
	2.6.1
	2.6.2
2.7	
	2.8.4
3.1	
	3.2.2
3.4	
3.5	
3.6	
	3.7.2
3.9	
3.10	
3.11	
3.12	
3.13	

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4.4	
4.6	
4.7	
4.8	
4.10	
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	5.1.4
	5.2.2
	5.4.3
6.1	
6.2	
6.4	
6.5	
6.6	
6.7	
	6.9.3
	6.10.1
6.13	

## Choice

All Criteria	Specific Criteria
	5.2.5
	5.2.6
5.4	
5.5	

## Clinical Governance

All Criteria	Specific Criteria
3.14	

## Clinical Psychology

All Criteria	Specific Criteria
	4.4.4
	4.5.2

## Commissioning

All Criteria	Specific Criteria
	1.5.1
	1.5.8
	3.1.6
	4.7.1
6.8	
	6.9.2
	6.10.2

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## Communication

All Criteria	Specific Criteria
	1.3.2
	2.3.5
	2.6.2
	2.6.3
	3.1.6
	3.1.7
	3.4.2
	3.4.3
	3.4.4
	3.12.4
	4.2.2
	4.3.2
	4.8.1
	4.8.3

## Community Based Services

All Criteria	Specific Criteria
1.3	
	1.5.3
3.3	
	3.4.7
4.3	
	4.4.3
4.7	
	4.9.4
	4.10.1
	4.10.5

## Community Health Partnerships (CHPs)

All Criteria	Specific Criteria
	1.4.3
	2.2.1
2.5	
	2.6.3
	3.3.2
5.1	
5.2	
5.4	
5.5	
6.1	
6.6	

## Community Learning Disability Services

All Criteria	Specific Criteria
	3.3.2
	3.6.3
	4.5.1
	4.5.6
	4.10.7
4.6	
	6.4.6

## Complaints

All Criteria	Specific Criteria
1.4	

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## Consent

3.5.1

## Consultation see Planning

## Co-ordinated Support Plans (CSPs)

All Criteria	Specific Criteria
	4.2.5

## Co-ordination

All Criteria	Specific Criteria
	2.6.3
	3.7.2
	3.7.3
	4.4.6
	4.5.6
	4.6.3
	4.8.6
	4.10.5
	4.10.6
	4.10.7
	4.11.1
	4.12.3
	4.14.2
	5.1.2

## Creative Therapies

All Criteria	Specific Criteria
	4.5.2

## Data Base

All Criteria	Specific Criteria
6.3	

## Data Protection

1.3.3

## Dementia

All Criteria	Specific Criteria
	4.6.2
4.12	

## Dental Services

All Criteria	Specific Criteria
	3.1.4

## Diagnosis

All Criteria	Specific Criteria
	4.11.2
	4.12.1

## Dietetics

All Criteria	Specific Criteria
	3.1.4
	4.4.4
	4.5.2

## Direct Payments

All Criteria	Specific Criteria
2.8	
	4.2.7

## Disability Discrimination Act/ Disability Awareness

All Criteria	Specific Criteria
2.1	
2.2	
3.10	



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## Dysphagia

All Criteria	Specific Criteria
	3.6

## Education

All Criteria	Specific Criteria
	2.5.1
	2.5.2
4.2	
	4.3.1
	4.4.7
	4.6.1
	4.7.2
	4.8.5
	4.11.2
	4.11.5
	4.13.3
	5.5.1

## Epilepsy

All Criteria	Specific Criteria
3.6	
	4.6.2
	4.13.1
	4.13.2
4.14	

## Evidence

All Criteria	Specific Criteria
	1.5.5
	1.6.4
	3.1.5
	3.1.6
4.8	
	6.2.2
	6.4.9
	6.6.2
6.8	

## Family Carers/Assessment of Needs

All Criteria	Specific Criteria
3.2	
6.1	

## Family Carers- Involvement of

All Criteria	Specific Criteria
1.1	
	1.2.3
	1.4.2
	1.4.4
	2.2.3
	2.4.4
	2.5.1
	3.1.5
	3.9.2
	3.10.5
	4.12.2

## Family Carers- Support to

All Criteria	Specific Criteria
1.5	
2.3	
2.7	
2.8	
	2.6.1
	3.2.1
	3.2.2
	3.3.4
	3.4.2
	3.5.3
	3.6.6
	4.1.2
	4.2.3
	4.3.3
	4.4.3
	4.7.5
	4.14.3
	4.14.4
	4.14.6

## Food and Diet

All Criteria	Specific Criteria
	5.5.4
	5.5.5

## Gender

All Criteria	Specific Criteria
	2.5.3
	5.4.6

## General Hospital Services

All Criteria	Specific Criteria
1.3	
	1.5.3
	1.6.7
	3.6.1
3.10	
3.11	
3.12	
	6.4.6

## Genetic Conditions

All Criteria	Specific Criteria
	4.6.2

## Guidance

All Criteria	Specific Criteria
	1.1.8
	1.5.5
	2.1.1
	2.2.2
	3.1.2
	3.2.1
	3.2.2
	3.5.1
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	3.10.2
	3.10.3
3.14	
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	4.2.7
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	5.1.3
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	5.4.6
5.5	
	6.3.2
	6.8.1
6.10	
	6.12.2
	6.12.3
	6.12.4

## Health Needs

All Criteria	Specific Criteria
	3.1.3
3.6	
	3.8.1
4.10	
	4.13.1

## Health Improvement/Health Promotion

All Criteria	Specific Criteria
2.5	
2.6	
	3.5.2
3.6	
6.1	
6.2	
	6.3.2

## Health Records

All Criteria	Specific Criteria
1.3	

## Health Screening

All Criteria	Specific Criteria
	3.1.4
3.5	
3.6	
	3.8.1

## Homelessness Services

All Criteria	Specific Criteria
	4.5.6
	6.1.5

## Hospital Closure

All Criteria	Specific Criteria
6.9	

## Hospital Services

All Criteria	Specific Criteria
1.3	
	1.5.3
3.11	
3.12	

## Inclusion

All Criteria	Specific Criteria
	2.5.6
	4.4.7
	4.6.1
	5.5.3
	6.2.1
	6.4.1

## Individual Education Plans (IEPs)

All Criteria	Specific Criteria
	4.8.5

## Information

All Criteria	Specific Criteria
	1.1.6
	1.3.1
	1.3.2
	1.4.1
1.6	
	2.5.1
2.6	
	2.7.1
	2.8.1
	2.8.4
	3.4.2
	3.5.3
	3.5.4
	3.6.6
	3.7.2
	3.10.5
	3.11.1
	4.1.2
	4.2.2
	4.2.3
	4.3.2
	4.3.3
	4.14.5
	5.5.6

## Inpatient Services

All Criteria	Specific Criteria
	4.7.8
	4.9.3
	4.10.1
	4.10.2
	4.10.4
	4.10.5
5	

## Intervention

3.8	
	4.4.1
	4.7.7
4.8	
	4.11.2
	4.12.2
	4.13.1

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6.10	

## Joint Working

All Criteria	Specific Criteria
	1.5.1
	2.5.5
3.1	
	3.3.2
3.7	
	3.8.3
	3.14.2
4.1	
4.2	
4.3	
4.4	
4.5	
	4.7.1
	4.7.2
	4.9.2
	4.10.2
	4.10.7
	4.11.2
	4.13.2
6.2	
6.3	
6.4	
6.6	
6.7	
6.10	
6.11	
6.12	
6.13	

## Leisure and Recreation

All Criteria	Specific Criteria
	2.5.2
	5.5.2

## Liaison see Co-ordination

## Local Area Co-ordination

All Criteria	Specific Criteria
	3.7.3
	4.4.6

## Local Authorities

All Criteria	Specific Criteria
	2.4.3
	2.5.5
	6.2.5
	6.9.1
	6.9.3

## Mainstream see Inclusion

## Managed Care Networks

All Criteria	Specific Criteria
	4.6.3
	4.9.6
	4.11.7

## Medication

All Criteria	Specific Criteria
3.6	
	4.12.2
	4.13.2
	4.14.5

## Mental Health

All Criteria	Specific Criteria
2.2	
3.6	
4.10	
	4.6.2
	4.12.4
	6.4.9

## Mental Health (Care and Treatment) (Scotland) Act 2003

All Criteria	Specific Criteria
	1.5.2
	3.10.3

## Mental Welfare Commission

All Criteria	Specific Criteria
	3.10.1
	4.8.1
	5.13

## Monitoring & Evaluation

All Criteria	Specific Criteria
	1.1.4
	1.4.2
	1.4.4
	1.4.5
	1.5.7
	2.1.3
	2.5.1
	2.5.7
	3.1.2
	3.6.4
	3.10.2
4.8	
	4.14.7
	5.1.1
	5.1.2
	5.1.3
	6.5.4
6.8	
6.10	
6.11	
	6.12.5

## National Care Standards

All Criteria	Specific Criteria
5.5	

## Nursing

All Criteria	Specific Criteria
	4.4.3
	4.4.4
	4.5.2
	4.14.4

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## Occupational Therapy

All Criteria	Specific Criteria
	4.4.4
	4.5.2

## Offending Behaviour

All Criteria	Specific Criteria
	4.6.2
4.9	

## Older People

All Criteria	Specific Criteria
3.8	
	4.2.8
	4.6.2
	4.12.4
	6.4.9

## Optometry

All Criteria	Specific Criteria
	3.1.4

## Orthodontics

All Criteria	Specific Criteria
	4.4.4

## Paediatric Services

All Criteria	Specific Criteria
	1.6.7
3.11	
3.12	
4.2	
	4.4.3
	4.4.4

## Palliative Care

All Criteria	Specific Criteria
3.13	

## Partnership in Practice Agreements

All Criteria	Specific Criteria
6.4	
	6.4.6
	6.4.7

## PEG Feeding

All Criteria	Specific Criteria
	4.13.2

## Person-centred Plans/Personal Life Plans

All Criteria	Specific Criteria
	1.2.2
	3.1.3
	5.5.1

## Physiotherapy

All Criteria	Specific Criteria
	4.4.4
	4.5.2

## Planning

All Criteria	Specific Criteria
1.1	
	1.5.1
2.4	
	3.4.1
5.1	
6.1	
6.2	
6.3	
6.4	
6.5	
6.6	
6.7	
6.8	
6.9	
6.10	
6.11	
6.12	

## Podiatry

All Criteria	Specific Criteria
	3.1.4
	4.4.4
	4.5.2

## Police

All Criteria	Specific Criteria
	4.9.2

## Policies & Procedures

All Criteria	Specific Criteria
1.1	
	1.2.1
1.3	
	1.4.1
	1.4.5
	1.4.6
	1.5.1
2.2	
2.5	
	3.7.2
	3.7.5
	3.8.2
	3.12.1
	4.2.1
	4.2.2
	4.3.1
	4.8.1
	4.8.2
	4.9.2
	4.9.5
	4.10.2
	4.11.8
	4.13.5
	5.1.3
	5.2.8
	6.2.5
	6.8.2
	6.10.1
	6.12.1
	6.12.4
	6.12.5
	6.13.1

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	1.6.7
3.3	
3.4	
	3.6.3
3.10	
	3.13.1
	4.1.1
4.2	
	4.11.5
	4.14.2
6.3	
	6.4.6

## Privacy

	1.6.2
5.3	
5.4	

## Probation

4.9.2

## Profound & Multiple Impairment

All Criteria	Specific Criteria
	2.3.4
	4.6.2
4.13	

## Promoting Health, Supporting Inclusion

All Criteria	Specific Criteria
6.4	

## Protocols see Policies & Procedures

## Psychiatry

All Criteria	Specific Criteria
	4.4.4
	4.5.2
	4.10.2

## Records

All Criteria	Specific Criteria
	1.2.3
1.3	
1.4	
	3.4.1
	3.4.3
	3.6.1
	3.7.2
	3.10.4
	3.12.5

## Referral

All Criteria	Specific Criteria
	1.6.5
	3.11.2

## Religion

All Criteria	Specific Criteria
	5.5.9

## Respite Care

All Criteria	Specific Criteria
	3.2.2
4.3	
	6.9.3

## Restraint

4.8.1

## Risk Assessment & Management

All Criteria	Specific Criteria
	3.7.5
4.8	
	4.9.3
5.1	
	5.3.3

## Rural & Remote

All Criteria	Specific Criteria
	6.2.3

## Screening see Health Screening

## Sensory Impairment

All Criteria	Specific Criteria
3.6	
	4.6.2

## Sexuality/ Sexual Health

All Criteria	Specific Criteria
	2.5.3

## Siblings

1.2.3  
1.5.4

## SIGN Guidelines

All Criteria	Specific Criteria
	3.14
	4.14.3

## Single Shared Assessment

All Criteria	Specific Criteria
	3.1.1
	4.4.8
	4.5.5
	6.3.3

## Smoking

5.4.7

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## Social Work & Social Care

All Criteria	Specific Criteria
3.7	
3.8	
	4.2.1
	4.3.1
	4.6.1
	4.7.2
	4.9.2
	4.11.2
	4.11.5
	4.13.2
	4.13.3
	4.13.5
	5.4.4

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## Speech and Language Therapy

All Criteria	Specific Criteria
	4.4.4
	4.5.2

## Specialist Support

All Criteria	Specific Criteria
	1.5.6
	2.7.3
	3.3.1
	3.6.2
	3.9.4
3.11	3.12.3
	3.12.6
	3.12.3
	3.13.2
	4.1.2
	4.3.5
4.4	
4.5	
	4.6.1
	4.6.2
	4.9.2
	4.11.2
	4.11.6
	4.13.2
	4.13.3
	4.14.1
	4.14.4
6.4	
	6.7.3

## Toilets

All Criteria	Specific Criteria
	2.3.4

## Training

All Criteria	Specific Criteria
	1.1.7
	1.4.5
1.6	
	2.2.1
	2.2.2
	2.2.3
	2.5.4
	2.7.2
	2.8.1
	3.1.2
3.10	
	3.11.2
	3.13.3
	4.7.3
	4.7.4
	4.8.2
	4.8.4
	4.8.5
	4.9.1
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	4.11.5
	4.12.3
	4.13.2
	4.13.3
	4.13.4

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	5.5.1
6.5	
	6.10.3
	6.12.2
	6.12.5
	6.13.2

## Transitions

All Criteria	Specific Criteria
	3.1.7
4.2	
4.3	
	6.4.5

## Transport

All Criteria	Specific Criteria
	2.3.3
2.4	

## User Involvement

All Criteria	Specific Criteria
1.1	
1.2	
1.3	
	1.4.2
	1.4.3
	1.4.4
1.5	
	2.2.3
	2.2.4
2.3	
	2.4.4
2.5	
	3.1.5
	3.8.2
	3.8.3
	3.9.1
	3.9.2
	3.10.5
	3.13.1
	5.4.2
	5.5.8
	6.9.1

## Vulnerable Adults

All Criteria	Specific Criteria
6.12	

## Waiting Times

All Criteria	Specific Criteria
	3.9.4
	3.10.4
	4.4.5
	4.5.3
	4.6.2

## Well Woman/ Well Men

All Criteria	Specific Criteria
	3.5.2

## Wheelchair Safety

All Criteria	Specific Criteria
3.9	

## Letter to advocacy groups and others

To:

Day centre managers  
 Provider organisations  
 Advocacy groups  
 Carer groups  
 Colleges  
 Employment services  
 Etc

Dear

We have just heard that the health services for people with learning disabilities in this area are to be reviewed by NHS Quality Improvement Scotland (NHS QIS) on ...

NHS QIS want to know how far we are meeting the needs of children and adults with learning disabilities and/or autistic spectrum disorders (ASD) and their families and what we can do to improve.

In order to assess our service we want to hear the experiences and views of children and adults with learning disabilities and their families. We have set aside resources for this work and we are asking for your help to work in partnership with us to engage people with learning disabilities and/or ASD and their families as meaningfully as possible.

The first thing we would like to do is to give you some information about the process so that you have as much warning as possible and know what to expect. NHS QIS have provided us with a pack of information including a CD. I enclose an easy read version introduction to the Quality Indicators and 'It's Our Health Service! Getting Healthy Staying Healthy' which tells you what NHS QIS thinks you should expect from the service and the kind of information we are looking for. I should be grateful if you could plan to discuss these in your group/ service.

We are working closely with our Patient and Public Involvement colleagues and the contact for information about the review is

....

We shall write to you shortly with details of a series of information days when we shall be very interested to hear your views on the best ways to engage with people with learning disabilities and their families.

## Letter to advocacy groups and others

We will be using a variety of ways to ask people their views and we expect to have a clear timetable for this by ....

After the Review you will be sent the report for comment. We hope very much that you will continue to work with us to improve our services for people with learning disabilities. From the review we hope to establish some ways of building comment and feedback from people with learning disabilities and/or ASD and family carers into the way that we monitor our services. We hope that some people will wish to join us in working out the best way to do this.

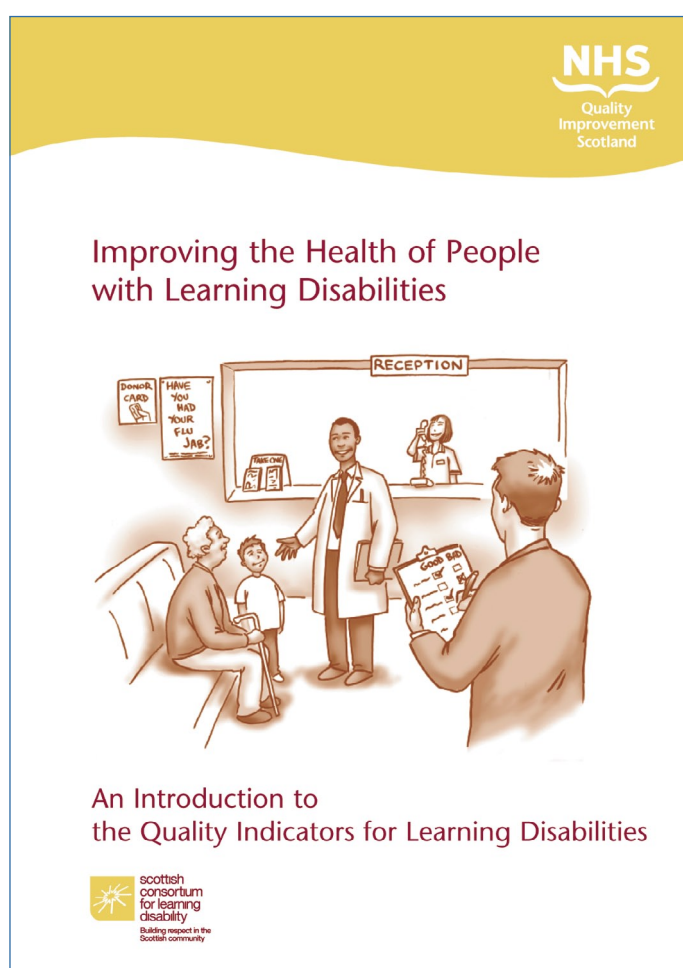


# It's Our Health Service! Getting Healthy Staying Healthy

NHS Quality Improvement Scotland (NHS QIS) has produced some quality indicators to help show if the health service is doing its job properly.

You can find out more about them in the booklet *Improving the Health of People with Learning Disabilities*.

This booklet tells you what the quality indicators say you can expect from your health services.



## To be listened to and have a say

You feel involved in deciding what a good health service is like.



Thanks to FAIR Multimedia

## You get support to feel good and lead a healthy life

This helps you take part in things you can enjoy.



From Food...Fun, Healthy and Safe

## Your doctor or nurse looks after your health

Your doctor or nurse keep an eye on your health and help you to stay well.



From Going to the Doctor



## If you have lots of health problems

You get the right support and are treated as an individual.

Your family gets support too!

From Michelle Finds a Voice



## If you have to stay in hospital for a long time

If you have to stay in hospital for a long time, you can make choices and keep your own things. You are treated with respect.

From A New Home in the Community



## What other people should do

Everyone in the health service has a responsibility to make sure that people with learning disabilities are not excluded and can benefit from their services.

From Getting on with Cancer

The pictures in this section are by

Catherine Brighton from Food...Fun, Healthy and Safe, Denise Redmond from Michelle Finds a Voice, Beth Webb from Going to the Doctor, A New Home in the Community and Getting on with Cancer.

## A Guide for parents and family carers

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### Introduction

The revised NHS QIS *Quality Indicators ~ Learning Disabilities* were published by NHS Quality Improvement Scotland in February 2004. They are used by NHS QIS to assess performance in NHS Board areas throughout Scotland.

Quality indicators are a way of assessing how well a service is performing. They aim to set targets which are challenging but achievable. NHS QIS expects services to be aiming to improve their own level of performance all the time (continuous improvement).

The revised *Quality Indicators ~ Learning Disabilities* apply to children and adults. They should be applied to all areas of the health service to improve the experiences of children and adults with learning disabilities and autistic spectrum disorders. They will also contribute to the developing Joint Inspections.

### How you can take part

Your local health service should be asking people for their views of the services they receive. Your views are relevant to the evidence required for the NHS QIS review. For example, if you are asked about the quality of the services, this information should be collected and used to improve the service.

As part of the NHS QIS review, your local health service has to do a 'self-assessment', that is to review its performance according to the quality indicators. You may be asked your views at this stage. We have recommended in the guidance pack to local health services that family carers should be consulted.

When the NHS QIS team comes to visit the service the team is likely to ask to meet some family carers or a carers' group. A sample questionnaire for family carers has been provided to NHS Boards.

When the report is published, you should expect to be able to get a copy and see what is being done to improve the service.

# A Guide for parents and family carers

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## A guide to the quality indicators

There are six quality indicators. They apply to different levels of health services. These are the quality indicators and why they are important (rationale):

### 1 **Involvement of children and adults with learning disabilities and their family carers through self-representation and independent advocacy**

This applies throughout the health service.

- Active involvement in planning and delivery helps to ensure services are provided on the basis of need.
- Services have a legal obligation to make sure information is available.
- Also to ensure advocacy services available.

### 2 **Promoting inclusion and wellbeing**

This applies to community services.

- People with learning disabilities should receive the same services and support.
- These should help to keep them healthy and enable them to participate fully in society.
- Health promotion and health improvement programmes should cater for different needs.

### 3 **Meeting general healthcare needs**

This applies to primary care, directly accessed services and general health or hospital services.

- People with learning disabilities can experience problems using primary care and general or hospital services which can mean that their health needs are not effectively assessed and met.
- Screening and assessment programmes should help to identify needs that are not being met and prevent health problems.
- Person-centred plans should help to ensure that the general and additional health needs of children and adults with learning disabilities are addressed.

## A Guide for parents and family carers

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### 4 Meeting complex healthcare needs

This applies to specialist learning disability services at local and area level.

- Children and adults with learning disabilities have a range of additional and complex needs, often life-long.
- To meet these needs, general and specialised services must be integrated across age and service transitions.
- Services to meet complex needs should be tailored to the individual and use evidence-based practice.

### 5 Inpatient services – daily life

This applies to specialist area health services.

- The quality of accommodation and services makes a key contribution to quality of life.
- People who use services are entitled to make choices and decisions about their life.

### 6 Planning services and partnership working

This applies to strategies and planning arrangements.

- Information on the needs of the population is essential to address health inequalities and plan services for children and adults.
- There must be effective partnership working and this calls for a strategic approach across NHS Boards, Community Health Partnerships and local authorities.
- The needs of children and adults with learning disabilities should be part of all planning activity and strategy documents.

### What should you expect services to be like?

Each quality indicator has a series of statements which set out the level of performance that is expected. These are the statements for each of the learning disability quality indicators.

#### 1 Involvement of children and adults with learning disabilities and their family carers through self-representation and independent advocacy

- 1.1 effective support for involvement in planning and delivery
- 1.2 involvement in the planning and review of their care across all health services



## A Guide for parents and family carers

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- 1.3 accessible policy on access to health records
- 1.4 policies and procedures in place for complaints, freedom of expression, recording suggestions and assessing satisfaction
- 1.5 strategy for the range of advocacy services
- 1.6 advocacy services promoted through training and access to information and services

## 2 Promoting inclusion and wellbeing

- 2.1 staff familiar with Disability Discrimination Act
- 2.2 up-to-date strategy for disability awareness and disability equality training
- 2.3 safe access to health service settings
- 2.4 transport services take account of the needs of children and adults with learning disabilities
- 2.5 agreed policy on health improvement and wellbeing takes account of the needs of children and adults with learning disabilities and addresses health inequalities
- 2.6 accessible information on the range of health services
- 2.7 services culturally sensitive and respond to the needs of black and ethnic minority children, adults and family carers
- 2.8 health services support people with learning disabilities to use direct payments

## 3 Meeting general healthcare needs

- 3.1 up-to-date multidisciplinary care plan
- 3.2 assessment of health and capacity of family carers is considered and linked to assessment of users' needs
- 3.3 named specialist practitioner linked to each primary care team
- 3.4 primary care services are responsive to the needs of children and adults with learning disabilities and their family carers
- 3.5 children, young people and adults with learning disabilities are included and supported to participate in national screening programmes
- 3.6 specific health needs are assessed and monitored
- 3.7 there is an agreed approach to joint working with social work and other agencies
- 3.8 appropriate health and social care intervention for older people with a learning disability

## A Guide for parents and family carers

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- 3.9 wheelchair and seating services provided
- 3.10 programme of education about rights and needs for healthcare professionals in all settings
- 3.11 paediatric and general hospital services can get help and support from specialist learning disabilities staff
- 3.12 general hospital services and paediatric hospitals/units aware of, and meet needs of, children and adults with learning disabilities
- 3.13 palliative care services take account of their needs
- 3.14 clinical guidelines followed and take account of their needs

## 4 Meeting complex healthcare needs

- 4.1 functions of specialised and general health services integrated
- 4.2 continuity of healthcare and liaison through transitions from preschool to school, primary to secondary education, youth to adult services and adult to older people's services
- 4.3 continuity of healthcare between services, eg community, respite, hospital, locality
- 4.4 access to specialist multidisciplinary community services for children
- 4.5 access to specialist multidisciplinary community services for adults
- 4.6 services provided for children and adults with complex needs across the area
- 4.7 community-based services for children and adults with challenging behaviour
- 4.8 evidence-based approaches to management and treatment of challenging behaviour
- 4.9 services for people with learning disabilities with offending behaviour
- 4.10 mental health needs of children and adults with learning disabilities are met in the most appropriate setting
- 4.11 assessment and treatment needs of adults and children with learning disabilities and ASD met according to national guidelines
- 4.12 appropriate range of services to meet needs of people with dementia
- 4.13 appropriate range of services to meet needs of children and adults with profound and multiple impairment and their family carers
- 4.14 services available for children and adults with learning disabilities who have epilepsy



## A Guide for parents and family carers

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### 5 Inpatient services – daily life

- 5.1 environment managed to reduce hazards and ensure safety
- 5.2 patient accommodation suitable and meets care home standards
- 5.3 privacy and property respected
- 5.4 individual needs, choice, privacy and dignity respected
- 5.5 people supported to make choices and decisions about daily life and how they spend their time

### 6 Planning services and partnership working

- 6.1 health improvement strategies take needs of children and adults with learning disabilities and family carers into account
- 6.2 measures to address health inequalities in line with the Health Needs Assessment report
- 6.3 electronic information on needs recorded (eCare)
- 6.4 healthcare plans for children and adults with a learning disability used in the Partnership in Planning Agreement (PiP) and other strategies
- 6.5 attention to workforce planning and the training and education needs of staff
- 6.6 Community Health Partnerships plan for the needs of children and adults with a learning disability
- 6.7 NHS Board has plans to develop services for children and adults with complex needs
- 6.8 when commissioning health services, NHS Boards use best information about what will make a difference
- 6.9 agreed plan on hospital closure and developing services in the community
- 6.10 joint arrangements for learning disability services
- 6.11 joint approach to services evaluation
- 6.12 there is a multidisciplinary group for the protection of vulnerable adults
- 6.13 there is a multidisciplinary group for the implementation of child protection policies

## A Guide for parents and family carers

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### Relevance to family carers

You will see that many aspects of the quality indicators may be of interest to family carers, depending on your situation and the needs of the person you care for.

For each statement there is a list of criteria that set out exactly what should be in place. You can read these in the full quality indicators.

The Toolkit of sample materials provided in this guide includes a questionnaire for family carers to complete.

### How to get the full document

The NHS QIS *Quality Indicators ~ Learning Disabilities* can be obtained from the following sources:

#### By post

NHS Quality Improvement Scotland  
Edinburgh Office  
Elliott House  
8-10 Hillside Crescent  
EDINBURGH  
EH7 5EA

The document is available on audio cassette or in large print.

#### On the web

It can also be seen on the NHS QIS website: [www.nhshealthquality.org/hhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf](http://www.nhshealthquality.org/hhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf)

#### From the SCLD library

The document can be borrowed from the library of the Scottish Consortium for Learning Disability.

Telephone: 0141 418 5420  
Email: [administrator@sclد.co.uk](mailto:administrator@sclد.co.uk)  
Website: [www.sclد.org.uk](http://www.sclد.org.uk)

# Using Experiences Effectively- including Toolkit

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## Introduction

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Part 4 concentrates on the appropriate use of methods to obtain views effectively. It highlights approaches that are most likely to be effective so that people's experiences can inform service development. The Toolkit contains sample materials to illustrate each method. These are mostly specific to a particular indicator, but the approach could be applied to a different topic. You can customise these materials for your own use as they are on the CD.

**Obtaining views – methods that work** reviews a range of data gathering methods and comments on ways to make them effective with people with learning disabilities.

**The Toolkit** contains sample materials.

There are many good guides on techniques for opinion gathering and public engagement and we particularly recommend the Toolkit produced by Partners in Change and published by the Involving People Team of NHSScotland. Here are some proven ways to make these methods work with people with learning disabilities.

## Obtaining views – methods that work

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### Obtaining views Top Tips

- ✓ Make sure the approach is friendly and relaxed. Do not be too formal.
- ✓ The people asking the questions should be approachable and dress casually. Ask a local advocacy group to explain the questions on which information is needed.
- ✓ Offer a range of ways for people to provide information.
- ✓ Try to make questions as close as possible to people's real experiences.
- ✓ Give information in order to receive it.
- ✓ Use facilitators who can record information in pictures (graphic facilitation).
- ✓ Offer people independent support.
- ✓ Build relationships with people – you will learn more.
- ✓ Treat people respectfully as valued informants.
- ✓ Work alongside support workers and advocates – they can help to get across what you want to know and to expand on what someone may be telling you, but don't let the support worker take over.
- ✓ Listen to people's stories – you can learn a great deal from experiences.
- ✓ People with learning disabilities may take longer to understand something. Allow plenty of time and breaks.

### Surveys

Many people with learning disabilities are often excluded from surveys that consider the quality and appropriateness of mainstream services. With support from people who can make information accessible, it should be possible to design a survey form that a person with learning disabilities can complete or can be supported to complete.

Ways to make questionnaires accessible to people with learning disabilities include:

- use symbols or pictures – consult your local speech and language teams to check that you are using a system that is likely to be familiar in your area
- do not just rely on symbols. Provide access to independent support and advocacy
- keep questions simple
- do not offer too many response categories

## Obtaining views – methods that work

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- give lots of explanation about what it is you are trying to find out
- make information available to supporters so that they can help to explain if necessary
- offer people the option of getting the information on tape or responding by tape or phone.

### Interviews

Interviews can be good ways to learn the views of people with learning disabilities as they give a bit of time for the person and the interviewer to get to know each other. There are lots of things that can be done to make interviews work well.

- Contact the person or their supporter beforehand to find a suitable time and place. Make sure the person has a meaningful way of knowing the appointment time. Don't give up if you don't manage to meet up at the first appointment.
- Check out what support the person will need and organise this.
- Offer as much preparation as possible. Let the person and their supporter know beforehand what you want to talk about.
- Be flexible – it may be best to ask direct questions or it may be best to listen to the person's story. Be responsive to how the person wants to communicate their experiences.
- Check out how the person can best understand you. Be prepared to ask things in different ways and to use pictures. Where appropriate check people's understanding by asking them to say what you have talked about.
- Don't be afraid to try things out – you are much more likely to succeed in communicating if you listen well, take your lead from the person and show that you are interested in what they have to offer you.

### Group discussions

Focus groups are a popular way of seeking opinions. They are a good way of finding out perceptions of people with a similar background on an issue, eg what a good service is like. They do not give you a count of how many people think one thing and how many another – unless you include a vote as well. Focus groups require experienced facilitators and note takers. The facilitator also needs to know how to support people with learning disabilities.

Ways to get the best out of a focus group with people with learning disabilities are:



## Obtaining views – methods that work

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- ✓ keep it small – four or five participants at most
- ✓ don't try to cover too much
- ✓ try to make it clear to everyone if the topic changes
- ✓ don't just talk – do things that people can join in with
- ✓ allow for the fact that not everyone thinks and speaks at the same pace
- ✓ use discussion triggers such as video clips
- ✓ make sure you have enough people to facilitate and note take – at least two
- ✓ offer frequent breaks and some social time
- ✓ ensure people have individual support, if needed, to take part
- ✓ check out if you have made it clear what you are asking
- ✓ meet people halfway – the facilitator may not at first see the relevance of what someone is trying to tell them.

This guide includes a suggested plan for organising a focus group of people with learning disabilities.

There are other group methods apart from focus groups. Good formats for getting opinions include small group work and story telling. You can use quizzes and competitions to convey information and check understanding.

Senior managers can benefit from the experience of observing such a group discussion. In market research it is common for the managers of a firm to be exposed directly to focus groups to understand how customers experience their service. This is much more powerful than reading flip charts!

## Accounts and stories

There is already a tradition in health service research of using stories of service experiences in order to understand what works well and what does not work in service delivery. Stories need not be mere 'anecdotes': they can be a rich source for learning about the quality of services if they are analysed and used well. They have the advantage of maximising what the user of the service knows about – their experience. The guide contains some examples of stories and some formats for obtaining and analysing these. Be creative – you can use games and activities to obtain stories and accounts. Remember that you must ask people's permission to use their stories. Stories should be anonymous unless the person wants to have their name on it. People should have access to independent support to tell or write their own story.

## Obtaining views – methods that work

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### Effective ways of using stories to gather views and improve quality

- ✓ Ask a local advocacy/self-advocacy group or a carers' group or family liaison worker to gather people's stories (experiences) of the service and to present these to you or to the review team with their suggestions of what would help to improve on these experiences.
- ✓ As part of your quality management, invite service teams to identify a random sample of service users and invite them to come to a workshop to tell their stories.
- ✓ Give a format to local service providers and groups and ask them to collect stories of service experience. Have these reviewed by senior managers and then hold a meeting to explain what changes you are thinking of making to improve services and seek feedback on these proposals.

## Obtaining views – methods that work

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### Interactive techniques

These are games or activities that can be used as another way of gathering anyone's views. It should not be assumed this is the only way to get opinions from people with learning disabilities. These techniques can be used as part of a discussion group or interview or on their own. For example, a quiz can be introduced as part of a focus group or an interviewer may ask someone to pick a card as a way of answering a question. Using these techniques provides the opportunity to ask further questions such as, 'why is that your favourite picture'?

Some ways to get the best out of these techniques with children and adults with learning disabilities are:

- ✓ explain clearly what the exercise is for and what you want people to do
- ✓ make sure the exercise is suitable for the preferred communication methods of the people you are working with
- ✓ plan the activity in detail and have all the materials to hand
- ✓ make sure that the activity reinforces the topic you are asking about
  - don't introduce new subjects that aren't relevant.

### Case studies

Case studies require good planning and preparation. They are a structured way of investigating and recording a particular situation in depth. Case studies can complement quantitative methods such as surveys by showing how and why a situation has developed as it has. A case study can combine information from a variety of sources and perspectives. Here are some top tips for good case studies:

- ✓ select your case study with care – you need to match the situation with the questions you want answers to.
- ✓ set some boundaries – place, time, people.
- ✓ get more than one viewpoint on the situation. You may use records and observations as well as interviews to get these.
- ✓ use a format of basic question, eg what happened here, what did it mean for those involved, what lessons can be learned?
- ✓ pay attention to how you will record the information – when do you need exact quotes and when are you looking for summaries? Consider using simple charts to pull together themes across different sources of data.
- ✓ set a time limit for collecting the information – you need time to pull the information together and draw out the implications
- ✓ consider using case studies to promote reflective learning across the service by building them into Continuing Professional Development (CPD) and portfolios.

## Toolkit

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### Introduction

The toolkit contains notes and sample materials to help you gather the views of people with learning disabilities and family carers. All the approaches identified in 'Obtaining views – methods that work' are illustrated here.

Most of the examples are based on finding views specific to a particular area of the indicators. But you can mix and match by adapting an approach to another area of the indicators that you wish to explore. The materials can be downloaded from the CD.

As well as sample materials you will find notes for interviewers and facilitators.

Please bear in mind that good practice in research ethics must be applied, whatever approach you adopt.

Method	Materials included	Respondents	Topic	NHS QIS Indicator ref
Survey	Questionnaire Guide in Part 3	Family carers	All	All
Survey	Key questions Guide in Part 3	People with learning disabilities	All	All
Interview	Notes for interviewer Interview schedule	Long-stay hospital resident	Daily life	5.5
Group discussion	Topic guide	People with learning disabilities and family carers	Support for involvement in planning	1.1.2
Focus group	Notes for facilitators Topic guide	People with learning disabilities	Accessible information	2.6.1
Stories	Notes Sample format Notes on analysis	People with learning disabilities	Responsiveness of primary care services	3.4
Interactive techniques	Notes Samples	Children	Healthy life	2.5.6
Case study	Notes	Planning stakeholders	Other strategies	6.4.9

## Questionnaire to family carers

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### Letter to accompany questionnaire

I am parent/carer to my 30-year-old daughter, Fiona, who has profound and multiple disabilities and complex medical needs, and have represented PAMIS (Promoting a More Inclusive Society) on the Scottish Health Advisory Service (SHAS) since 1999, on its Learning Disability Users and Carers Group. When SHAS merged with NHS Quality Improvement Scotland (NHS QIS), I became a member of the Project Group for Learning Disability as well as being a reviewer on NHS QIS reviews of NHS Boards around Scotland.

On these reviews, the QIS Review team meets healthcare managers and staff to hear of the services in place and also consults with carers and people with learning disabilities, as service users. This is an important part of the review. There is always a carer and a person with a learning disability working in the team.

Also as part of each review, other carers are given the opportunity to meet the reviewers to tell them of their experiences, both good and bad, of health services provided for the people they care for. This helps to highlight good practices that can be shared with others and also assists in identifying areas for possible improvement. This information links with the other information gathered by NHS QIS to allow it to report its findings to NHS Boards to help them better plan for the future.

The Scottish Consortium for Learning Disability (SCLD) and NHS QIS have together designed this questionnaire specifically for carers, to help guide their input in a consistent and helpful manner. The questionnaire is a valuable tool in giving information to NHS QIS and the NHS Boards on how well, or not so well, the NHS Board is delivering its services to you and the people you care for. As a carer, your health is vitally important too and this should not be forgotten.

Good healthcare is recognised as a key to a healthy life and this is equally so for people with learning disabilities and their carers. It is extremely encouraging, and forward looking, that NHS QIS has recognised the importance of giving carers, and the people they care for, such a good opportunity to be an integral part of the review process so please use this questionnaire to let the review team know your experiences and help plan for a better future.

Thank you.

Anne Brown

## Questionnaire to family carers

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The following inset section is available on the CD in Word, so that it can be customised for your needs.

Notes

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# **Improving the Quality of Health Services for People with Learning Disabilities and/or Autistic Spectrum Disorder and their Families**

## **Questionnaire to Family Carers**

The health service wants to ensure that it is meeting the needs of all its patients. We understand you care for a family member with learning disabilities and/or autistic spectrum disorder (ASD). Please tell us about your experiences of the health service in this area and your views about its quality. We hope to learn from these to improve the service. We would welcome your ideas on how we could improve the health service for people with learning disabilities and their families.

The questionnaire may take about 20 minutes to complete. If you care for a child, a person with complex health needs or with profound disability, you will find that there are some additional questions.

The questions provide information relevant to the quality indicators for learning disability health services developed by NHS Quality Improvement Scotland (NHS QIS). You do not need to put your name on the questionnaire. When you have filled it in please return it in the envelope provided to the address at the end of the questionnaire.

**[Add your logo here]**



## 1. Being involved

**These questions are about how well you feel the local health service actively involves children and adults with learning disabilities and/or ASD, and family carers, in the planning and delivery of services.**

### 1.1 How much do you feel that you get a chance to give your views about the healthcare and treatment of the person you care for?

- |               |                          |   |
|---------------|--------------------------|---|
| A great deal  | <input type="checkbox"/> | 1 |
| Quite a lot   | <input type="checkbox"/> | 2 |
| Not very much | <input type="checkbox"/> | 3 |
| Hardly at all | <input type="checkbox"/> | 4 |
| Not sure      | <input type="checkbox"/> | 9 |

### 1.2 How much do you feel that your local health service listens to family carers?

- |               |                          |   |
|---------------|--------------------------|---|
| A great deal  | <input type="checkbox"/> | 1 |
| Quite a lot   | <input type="checkbox"/> | 2 |
| Not very much | <input type="checkbox"/> | 3 |
| Hardly at all | <input type="checkbox"/> | 4 |
| Not sure      | <input type="checkbox"/> | 9 |

### 1.3 If you wish, please give an example of how the service does or does not listen to family carers

**1.4 Have you ever taken part in an activity to plan or improve the service?**

YES ☐ 1

How was this achieved?

Planning Group ☐ 10

Written Consultation ☐ 11

Consultation Meeting ☐ 12

Survey or other research ☐ 13

Taking part in staff training ☐ 14

**Have you ever taken part in an activity to plan or improve the service?**

Other ☐ 15

Please say what this was

NO ☐ 2

NOT SURE ☐ 9

**1.5 In your experience, how easy or difficult is it to find the information you need about the health services in your area?**

Very easy ☐ 1

Quite easy ☐ 2

Quite difficult ☐ 3

Very difficult ☐ 4

Not sure ☐ 9

**1.6 Do you have any suggestions for improving information about the health services in your area?**

**1.7 Has the person you care for ever had an independent advocate?**

Yes	<input type="checkbox"/>	1
No	<input type="checkbox"/>	2
Not sure	<input type="checkbox"/>	9

**1.8 Have you ever seen, or heard about, any information about how to get an advocate?**

Yes	<input type="checkbox"/>	1
No	<input type="checkbox"/>	2
Not sure	<input type="checkbox"/>	9

## 2. Feeling well and being included

These questions are about whether people with learning disabilities and/or ASD get the same services and support as everyone else to keep them healthy, and to enable them to play a full part in society. We also want to know whether the health service is able to provide them with information and support about staying healthy that is appropriate for their needs.

### 2.1 For the person you care for, are health service premises –

- |                       |                          |   |
|-----------------------|--------------------------|---|
| Fully accessible      | <input type="checkbox"/> | 1 |
| Fairly accessible     | <input type="checkbox"/> | 2 |
| Not very accessible   | <input type="checkbox"/> | 3 |
| Not accessible at all | <input type="checkbox"/> | 4 |
| Not sure              | <input type="checkbox"/> | 9 |

### 2.2 Please tell us about problems the person you care for has experienced recently with access to health service premises

### 2.3 Does the person you care for experience any problems with transport?

- |               |                          |   |
|---------------|--------------------------|---|
| A great deal  | <input type="checkbox"/> | 1 |
| Quite a lot   | <input type="checkbox"/> | 2 |
| Not very much | <input type="checkbox"/> | 3 |
| Hardly at all | <input type="checkbox"/> | 4 |
| Not sure      | <input type="checkbox"/> | 9 |

**2.4 Please tell us what the issues are with transport, and what would help**

**2.5 Has the person you care for received information that they can understand, about**

Food / Nutrition	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Keeping Active	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Feeling Good	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Relationships	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Any other information about keeping healthy

Yes	No	Not sure
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Please say what.....

**2.6 Which of these topics do you think it is important for them to have information about?**

Food / Nutrition	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Keeping Active	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Feeling Good	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Relationships	Yes	No	Not sure
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Any other information about keeping healthy

Yes	No	Not sure
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 9

Please say what.....

**2.7 Please tell us about anything that would really help to make the information available to them**

**2.8 Does the person you care for get any other kinds of help about staying healthy?**

- |          |                          |   |            |
|----------|--------------------------|---|------------|
| Yes      | <input type="checkbox"/> | 1 | GO TO 2.9  |
| No       | <input type="checkbox"/> | 2 | GO TO 2.10 |
| Not sure | <input type="checkbox"/> | 9 |            |

**2.9 Who provides this help, and what help do they give?**

**2.10 Is there any kind of help they are not getting at the moment that you think would make a difference to their health?**

**2.11 In general how well aware do you feel that local health service staff are about disability issues?**

- |                  |                          |   |
|------------------|--------------------------|---|
| Very aware       | <input type="checkbox"/> | 1 |
| Fairly aware     | <input type="checkbox"/> | 2 |
| Not very aware   | <input type="checkbox"/> | 3 |
| Not aware at all | <input type="checkbox"/> | 4 |
| Not sure         | <input type="checkbox"/> | 9 |

### 3. General health services

**These questions are about your local surgery, general hospitals, and health services that are not specific to people with learning disabilities**

#### 3.1 How much do you feel your family doctor understands about the needs of the person you care for?

A great deal ☐ 1

Quite a lot ☐ 2

Not very much ☐ 3

Hardly at all ☐ 4

Not sure ☐ 9

#### 3.2 How well do you feel that health service professionals communicate with the person that you care for?

Very well ☐ 1

Quite well ☐ 2

Not very well ☐ 3

Not well at all ☐ 4

Not sure ☐ 9

#### 3.3 Please comment if you wish



**3.4 How well do you think that the health needs of the person you care for are assessed and monitored?**

Very well ☐ 1

Quite well ☐ 2

Not very well ☐ 3

Not well at all ☐ 4

Not sure ☐ 9

**3.5 If you or local health services needed support from a health care professional with specialist knowledge of the needs of people with learning disabilities and/or ASD, do you feel that this support would or would not be available?**

Definitely would ☐ 1

Probably would ☐ 2

Probably would not ☐ 3

Definitely would not ☐ 4

Not sure ☐ 9

**3.6 Has the person you care for *needed* any new/replacement specialist equipment within the last 12 months?**

Yes ☐ 1 GO TO 3.7

No ☐ 2 GO TO 3.9

Not sure ☐ 9

### 3.7 What equipment did they need?

--

**3.8 How easy or difficult was it to get the equipment that they needed?**

- Very easy ☐ 1
- Fairly easy ☐ 2
- Neither easy nor difficult ☐ 3
- Fairly difficult ☐ 4
- Very difficult ☐ 5
- Not sure ☐ 9

**3.9 Has the person you care for been admitted to hospital within the last 12 months?**

- Yes ☐ 1 GO TO 3.10
- No ☐ 2 GO TO 3.11
- Not sure ☐ 9

**3.10 And how well do you feel the hospital staff were able to meet the needs of the person you care for?**

- Very well ☐ 1
- Quite well ☐ 2
- Not very well ☐ 3
- Not well at all ☐ 4
- Not sure ☐ 9

**3.11 Are there any ways in which hospitals could better meet the needs of people with learning disabilities and/or ASD?**

**3.12. How well do you feel that your needs as a family carer, including your health needs, have been taken into account?**

Very well ☐ 1

Quite well ☐ 2

Not very well ☐ 3

Not well at all ☐ 4

Not sure ☐ 9

**3.13 Is there any kind of help you are not getting at the moment that you think would make a difference to your health?**

## 4 Specialist services

**This is about specialist services for people with additional and complex needs.**

### 4.1 Does the person you care for need any specialist services because of any one or more of the following

*Challenging behaviour*

*Offending behaviour*

*Mental health problems*

*Autistic Spectrum Disorder*

*Dementia*

*Profound and Multiple Impairment*

*Epilepsy*

*Other complex needs*

Yes ☐ 1 GO TO 4.2

No ☐ 2 GO TO 5.1

Not sure ☐ 9

### 4.2 How easy or difficult has it been to access the specialist services that they need?

Very easy ☐ 1

Fairly easy ☐ 2

Neither easy nor difficult ☐ 3

Fairly difficult ☐ 4

Very difficult ☐ 5

Not sure ☐ 9

#### **4.3 Please tell us about this**

#### **4.4 How well would you say that information is shared between the different health professionals who look after the person you care for?**

- |                 |                          |   |
|-----------------|--------------------------|---|
| Very well       | <input type="checkbox"/> | 1 |
| Quite well      | <input type="checkbox"/> | 2 |
| Not very well   | <input type="checkbox"/> | 3 |
| Not well at all | <input type="checkbox"/> | 4 |
| Not sure        | <input type="checkbox"/> | 9 |


#### **4.5 How well do you feel that the different services involved with the person you care for work together?**

- |                 |                          |   |
|-----------------|--------------------------|---|
| Very well       | <input type="checkbox"/> | 1 |
| Quite well      | <input type="checkbox"/> | 2 |
| Not very well   | <input type="checkbox"/> | 3 |
| Not well at all | <input type="checkbox"/> | 4 |
| Not sure        | <input type="checkbox"/> | 9 |

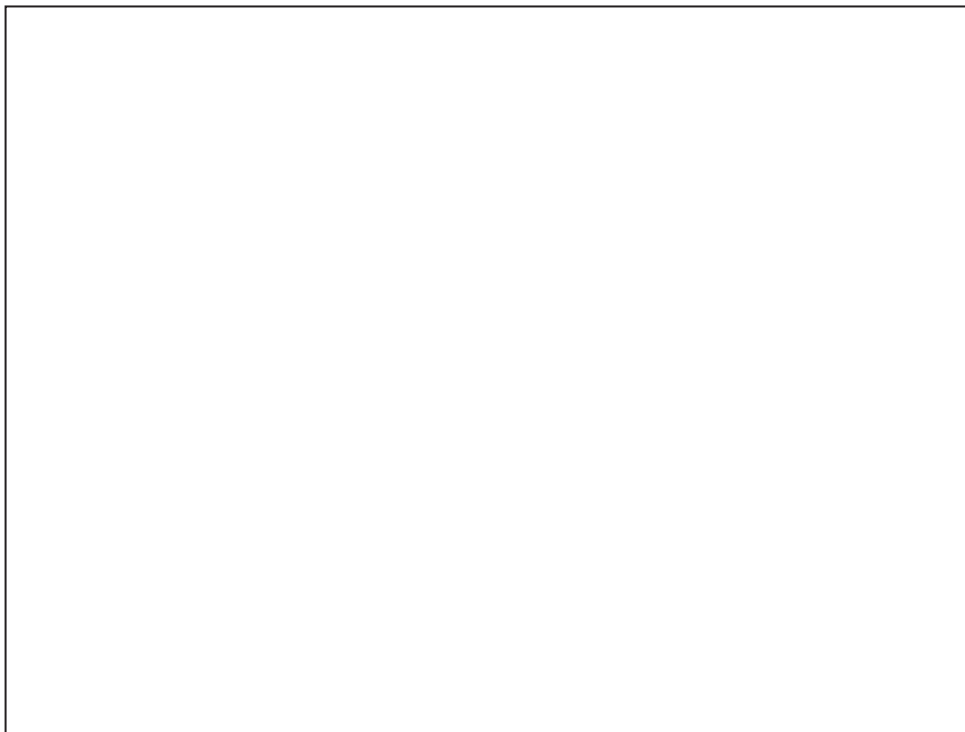
#### **4.6 Please tell us any suggestions you have for how this could be improved**



**4.11 Can you tell us the best thing that the health service has done to improve the life of the person you care for?**



**4.12 Can you tell us the improvement you would most like to see in the care that the health service does or does not give to the person you care for?**



## **5 The quality of services for people living in hospital**

This is about services for people who have to live in a hospital or healthcare setting – for example for assessment and treatment or for respite.

### **5.1 In the past 12 months has the person you care for ever lived in a hospital or health care setting?**

- |          |                          |   |           |
|----------|--------------------------|---|-----------|
| Yes      | <input type="checkbox"/> | 1 | GO TO 5.2 |
| No       | <input type="checkbox"/> | 2 | GO TO 6.1 |
| Not sure | <input type="checkbox"/> | 9 |           |

### **5.2 When living in that setting, how much choice do you feel that they had in their daily life?**

- |                 |                          |   |
|-----------------|--------------------------|---|
| A great deal    | <input type="checkbox"/> | 1 |
| Quite a lot     | <input type="checkbox"/> | 2 |
| Not very much   | <input type="checkbox"/> | 3 |
| Not much at all | <input type="checkbox"/> | 4 |
| Not sure        | <input type="checkbox"/> | 9 |

### **5.3 And how much privacy do you feel that they had there?**

- |                 |                          |   |
|-----------------|--------------------------|---|
| A great deal    | <input type="checkbox"/> | 1 |
| Quite a lot     | <input type="checkbox"/> | 2 |
| Not very much   | <input type="checkbox"/> | 3 |
| Not much at all | <input type="checkbox"/> | 4 |
| Not sure        | <input type="checkbox"/> | 9 |



**5.4 Please tell us any suggestions you have that you feel could improve the quality of life for people living in hospitals or health settings**

## 6 Planning services and joint working

**These questions are about what is being done to make sure that the right services are available to everyone.**

### 6.1 How much say do you feel that you have in the running of the health services in your area?

- |                 |                          |   |
|-----------------|--------------------------|---|
| A great deal    | <input type="checkbox"/> | 1 |
| Quite a lot     | <input type="checkbox"/> | 2 |
| Not very much   | <input type="checkbox"/> | 3 |
| Not much at all | <input type="checkbox"/> | 4 |
| Not sure        | <input type="checkbox"/> | 9 |

### 6.2 How well do you think that the health service works with other organisations to look after the interests of people with learning disabilities in your area?

- |                 |                          |   |
|-----------------|--------------------------|---|
| Very well       | <input type="checkbox"/> | 1 |
| Quite well      | <input type="checkbox"/> | 2 |
| Not very well   | <input type="checkbox"/> | 3 |
| Not well at all | <input type="checkbox"/> | 4 |
| Not sure        | <input type="checkbox"/> | 9 |

### 6.3 Do you feel that the health services in your area do or do not give enough attention to the needs of people with learning disabilities?

- |                   |                          |   |
|-------------------|--------------------------|---|
| Definitely do     | <input type="checkbox"/> | 1 |
| Possibly do       | <input type="checkbox"/> | 2 |
| Possibly do not   | <input type="checkbox"/> | 3 |
| Definitely do not | <input type="checkbox"/> | 4 |
| Not sure          | <input type="checkbox"/> | 9 |

## 7 The person you care for

This section asks for some information about the person you care for. It is only needed so that we can see how representative our survey is.

### 7.1 Are they

A man ☐ 1

A woman ☐ 2

### 7.2 Is their age, in years

0 - 4 ☐ 1

5 - 9 ☐ 2

10 - 14 ☐ 3

15 - 19 ☐ 4

20 - 24 ☐ 5

25 - 34 ☐ 6

35 - 44 ☐ 7

45 - 54 ☐ 8

55 - 64 ☐ 9

65 - 74 ☐ 10

75 - 84 ☐ 11

85 or older ☐ 12

## 8 You

This asks for some information about you. It is only needed so that we can see how representative our survey is.

### 8.1 Are you

A man ☐ 1

A woman ☐ 2

### 8.2 Is your age in years

0 - 4 ☐ 1

5 - 9 ☐ 2

10 - 14 ☐ 3

15 - 19 ☐ 4

20 - 24 ☐ 5

25 - 34 ☐ 6

35 - 44 ☐ 7

45 - 54 ☐ 8

55 - 64 ☐ 9

65 - 74 ☐ 10

75 - 84 ☐ 11

85 or older ☐ 12

**8.3 Please say which, if any, of the words below describes the way you think of yourself. Please choose as many or as few as apply.**

- |                           |                          |    |
|---------------------------|--------------------------|----|
| British                   | <input type="checkbox"/> | 1  |
| English                   | <input type="checkbox"/> | 2  |
| European                  | <input type="checkbox"/> | 3  |
| Irish                     | <input type="checkbox"/> | 4  |
| Northern Irish            | <input type="checkbox"/> | 5  |
| Scottish                  | <input type="checkbox"/> | 6  |
| Ulster                    | <input type="checkbox"/> | 7  |
| Welsh                     | <input type="checkbox"/> | 8  |
| Other                     | <input type="checkbox"/> | 9  |
| <div></div>               |                          |    |
| None of these             | <input type="checkbox"/> | 10 |
| Other - Asian             | <input type="checkbox"/> | 11 |
| Other – African/Caribbean | <input type="checkbox"/> | 12 |

**8.4 And if you had to choose, which one BEST describes the way you think of yourself?**

- |                           |                          |    |
|---------------------------|--------------------------|----|
| British                   | <input type="checkbox"/> | 1  |
| English                   | <input type="checkbox"/> | 2  |
| European                  | <input type="checkbox"/> | 3  |
| Irish                     | <input type="checkbox"/> | 4  |
| Northern Irish            | <input type="checkbox"/> | 5  |
| Scottish                  | <input type="checkbox"/> | 6  |
| Ulster                    | <input type="checkbox"/> | 7  |
| Welsh                     | <input type="checkbox"/> | 8  |
| Other                     | <input type="checkbox"/> | 9  |
| <div></div>               |                          |    |
| None of these             | <input type="checkbox"/> | 10 |
| Other - Asian             | <input type="checkbox"/> | 11 |
| Other – African/Caribbean | <input type="checkbox"/> | 12 |

## 8.5 To which of these groups do you consider you belong?

BLACK: of African origin ☐ 1

BLACK: of Caribbean origin ☐ 2

BLACK: of other origin ☐ 3

ASIAN: of Indian origin ☐ 4

ASIAN: of Pakistani origin ☐ 5

ASIAN: of Bangladeshi origin ☐ 6

ASIAN: of Chinese origin ☐ 7

ASIAN: of other origin ☐ 8

WHITE: of any European origin ☐ 9

WHITE: of other origin ☐ 10

MIXED ORIGIN ☐ 11

OTHER ☐ 12

## 8.6 What is your relationship to the person you care for?

Parent ☐ 1

Brother/Sister ☐ 2

Other ☐ 3

Please say what....

**Thank you for your help.**

**Please return this questionnaire in the envelope provided to:**

**[Add return details here]**

**If you have any questions or concerns please contact:**

**[Add contact in NHS Board/local authority here]**

## Key questions for people with learning disabilities

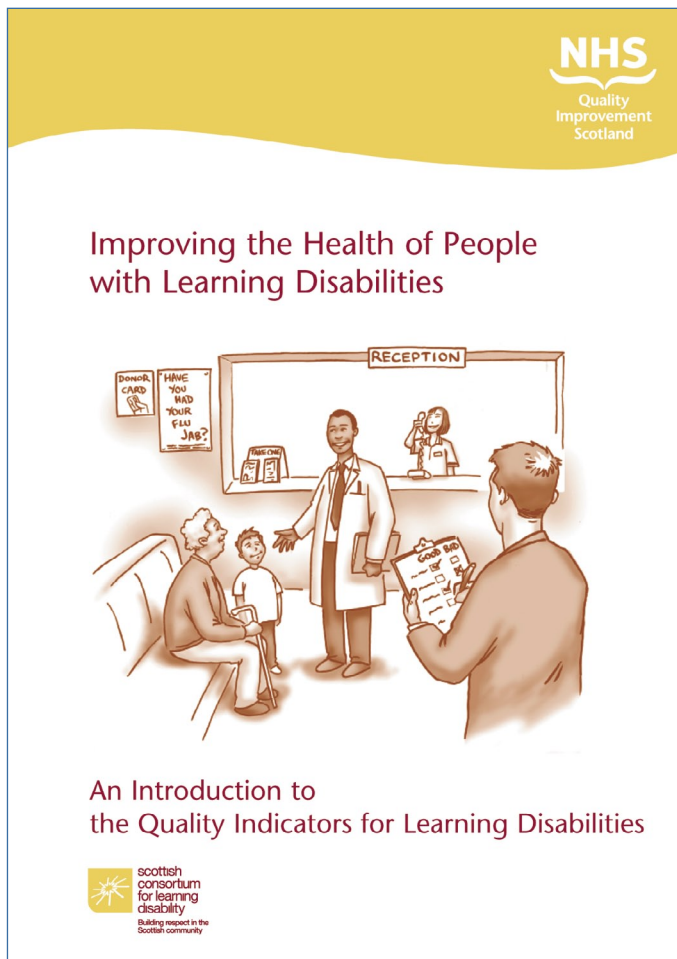
# It's Our Health Service! Getting Healthy, Staying Healthy

Your local health service wants to know if it is helping you to get healthy and stay healthy.

Please tell us what you think.

This will help us to improve the service

Please ask your local health service to use the symbols that will be understood in your area for the questions in this booklet.





## Key questions for people with learning disabilities

### Being Listened to and Having a Say



Do you feel that your doctor or nurse listens to what you say?

Do you get a chance to say what you think about the health services you get?

Have you ever had an independent advocate?

Could you get an independent advocate if you needed one?

Thanks to FAIR Multimedia



### Getting Support to Feel Good and Lead a Healthy Life

Can you get information, that you can understand, about being healthy?

Do you get any help to live a healthy life?

From Food...Fun, Healthy and Safe



### Your Doctor or Nurse Looking After Your Health

Do you get the support you need when you see your doctor?

Does your doctor or nurse help you to look after your health?

From Going to the Doctor

## Key questions for people with learning disabilities

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From Michelle Finds a Voice

### **If You have Lots of Health Problems**

Do you get help to stay well from people who know about your health needs?

Do the different staff you have to see work well together?



From A New Home in the Community

### **If You Have to Stay in Hospital for a Long Time**

Do you get to choose what happens each day?

Do you have your own stuff with you in the hospital?



From Getting on with Cancer

### **What Other People Should Do**

Do people with learning disabilities get the right health services in this area?

How easy or difficult is it to get another service if you need it?

Is there anything else you would like to tell us?

The pictures in this section are by

Catherine Brighton from Food...Fun, Healthy and Safe, Denise Redmond from Michelle Finds a Voice, Beth Webb from Going to the Doctor, A New Home in the Community and Getting on with Cancer.

## Toolkit

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### Method: Interview

### Participant: Long- stay hospital resident

### Topic: Inpatient services – daily life

### NHS QIS Quality Indicator Reference: 5.5

#### **Privacy and Personalisation (Quality Indicator Statement 5.4)**

‘The NHS Board/Community Health Partnership provides an environment supportive of individual needs, choice, privacy and dignity’

### Notes for interviewers

This is an example where evidence from the experiences of a hospital resident could be very useful. A sample interview framework is included. This would have to be adapted according to the communication needs of the person. The interviewer could be a health service researcher or an advocate.

#### **Before the interview**

Before talking to someone it is important that they are told what the interview is about so that they can choose whether to take part. You must ensure that you can obtain informed consent. If the person is not able to give their consent refer to the Welfare Guardian. Arrange for a trusted individual such as their advocate to be present if possible.

Before the interview find out the person’s preferred methods of communication and make sure that they are offered the support that they need. The speech and language therapy service should be able to help here.

It is important that the person can be assured that what they say will not be used against them, and that they do not have to answer any questions they do not like. You should explain to staff on the ward that you will not be identifying individuals in your report.

The interviewer must be familiar with the vulnerable adults procedure so that they are clear what to do if the person alleges abuse, or if the interviewer suspects abuse. It is essential that the person being interviewed is told at the beginning that what is being discussed will be confidential, **but** serious matters such as this will be acted upon.

If an individual wants information about themselves to be withheld from someone, or some organisation, the individual's wishes should be respected unless there are exceptional circumstances. The exceptional circumstances which override an individual's wishes arise when:

- where there is a serious public health risk of harm to other individuals
- for the prevention, detection or prosecution of serious crime
- where there is a serious health risk of harm to self.

There needs to be a balance between the requirements of confidentiality and the consideration that, to protect vulnerable adults, it may be necessary to share information on a 'need-to-know basis'.

The following quote comes from 'No Secrets' (Department of Health)

'it is inappropriate for agencies to give assurances of absolute confidentiality in cases where there are concerns about abuse, particularly in those situations when other vulnerable people may be at risk'

Make sure that the service has given some thought to how people will find out if any changes are made to the service as a result of listening to people's experiences.

### **The interview itself**

Find a place where the person feels comfortable and you can talk privately. This does not necessarily mean you have to spend the whole interview in a side room where the person will have no external clues as to what you are interested in. You may want to walk around with the person a bit. Both the interviewer and the resident will probably get the most out of the interview if as far as possible they talk about real things - places you can see, people you can meet, etc.

The principles at the core of this quality indicator statement ensure that the person should be enabled to make choices, to express their individuality, to enjoy privacy and to be treated with dignity. An interviewer needs to get a feel for the person's daily life and how far they experience choice as a day-to-day reality. They also need to find out whether the service is actively supporting the resident to have as much choice as possible.

In this example the interviewer asks relatively open-ended questions about the person's everyday life, ie questions that require an answer other than 'yes' or 'no'. They should follow up with prompts or questions specific to that person's life to find out how much choice they have. The interviewer is provided with a checklist, to remind them about topics they may wish to

cover, that relate to the quality indicators.

Don't stick rigidly to a predetermined schedule. Be ready to go with what the person has to tell you and check out the things you want to know by following up specific points.

The interviewer should record specific details that the person tells them or shows them. At the end the interviewer should record their own observations. They should share these with the person they have interviewed. It is very important to thank the person for their time. Tell them what they can expect in terms of feedback.

### **After the interview**

Write up your notes as soon as possible after the interview. Wherever possible use the person's own words and always put these in quotes. It may also be helpful to add your own notes to explain the comments. The checklist can be used to organise the material under themes. Try to avoid the kind of detail that might identify the individual. For example if the person mentions their brother you may want to write 'a close relative'.

Make sure you have left time to refer immediately and appropriately any pressing issues about the person's care or concerns they may have voiced, taking account of the NHS Code of Practice on Protecting Patient Confidentiality (2003).

You must also follow good practice in research ethics (see Resources in Part 5).

## Toolkit

## Interview with long-stay hospital resident

## Sample interview with long-stay hospital resident

Date  
 Hospital  
 Ward  
 Advocate present? YES/NO  
 Communication checked? YES/NO  
 Communication support provided? YES/NO  
 How has consent been obtained?

Hello

Thank you for talking to me. Can I just check, is it ok for you to speak to me just now?

Tell me about your day. When do you get up, most days? ...

Sample prompt: Can you stay in bed late if you want to?

checklist
CHOICE
who live with
ward moves
daily activities
money
food
snacks
clothes
beliefs

Who helps you to do the things your way? ...

Support for choice

Do you have something, or someone, really special?

OR:

Is there something you like to do best of all?

Sample prompt: Is it ok for you to spend time with this (them)?

checklist
INDIVIDUAL
room
adaptations
leisure
relationships

Are your own things safe here?

Sample prompt: Is there anyone you could tell a secret to?

checklist
PRIVACY
space
Possessions
personal affairs

Do you feel respected here?

Sample prompt: Do people listen if you say 'no'?

checklist
DIGNITY
respect
care
feelings

SUMMARY

Is there anything else you want to say?

Thank you for your time and for answering my questions.

CHOICE
INDIVIDUALITY
PRIVACY
DIGNITY

## Toolkit

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**Method: Group discussion**

**Participants: Planning group representatives**

**Topic: Is there appropriate support available to ensure effective involvement in planning groups?**

**NHS QIS Quality Indicator Reference: Criterion 1.1.2**

### **Topic guide for facilitator**

Tell me a bit about the group(s) you are involved with? What do they do?

What things help you to take part in the group?

- time to prepare
- support
- breaks
- opportunity to speak
- accessible information

What things make it hard for you to take part in the group?

Has the planning group changed anything?

If so, what change has it made and how important is this?

Do you feel you have made a difference by being on the group?

Tell me about a time when you found the group really useful.

Tell me about your worst moment on the group.

Are there other kinds of people who should be on the group?

Do you think that enough people know about the group and what it does?

What are your top tips for making sure that groups like this really involve people?



## Toolkit

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### Method: Focus Group

### Participants: Adults with learning disabilities

### Topic: accessible information

### NHS QIS Quality Indicator Reference: Criterion 2.6.1

### Promoting inclusion and wellbeing

Information is available for children and adults with learning disabilities and their family carers about healthcare issues and wellbeing, in appropriate formats, across all healthcare settings.

### Notes for facilitators

Keep the group small - at most five people with learning disabilities. Ensure that the participants can bring supporters with them if required. Make sure they have had plenty of notice about what the group will discuss. You will need one person to facilitate the group and another to record - perhaps on a flip chart using graphics. Make sure you have lots of examples of information for the group to look at. Your speech and language therapy service and health promotion library could be a big help here. You will find some suggestions of health leaflets for people with learning disabilities in the Resources section of this guide (Part 5).

This is a pick and mix menu. You might cover one or two of these ideas in a 2 hour session or deal with them over several sessions. Allow for frequent breaks.

You can use the information from this group to find out:

- what people think is important to make information accessible
- what styles of information people like
- what support people might need to get involved in helping to produce accessible information.

Afterwards it will be important to think about how the information from the group will be used. Does it help to evaluate existing information, to assist with criteria for assessing accessibility, or to suggest new information that may be needed? Maybe the group could continue to help with this.



## Toolkit

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### Topic guide

#### Icebreaker

Ask everyone to find another member of the group. They have to tell each other their name and something about themselves, eg their favourite food.

#### Quiz

You may want to set up two teams. Do a quiz and then use it to start a discussion on what makes good information. For example:

- 1 What makes information easy to understand? Is it...
  - A simple words
  - B lots of numbers
  - C tiny wee print
  
- 2 What helps people who cannot see?. Is it...
  - A shouting loudly
  - B putting information on tape
  - C using bright colours
  
- 3 Who gets their message across best? Is it...
  - A Tony Blair
  - B Bart Simpson
  - C David Beckham
  
- 4 Which do you remember best? Is it...
  - A your favourite advert
  - B your team's last score
  - C the weather last Saturday?

Let members of the group tell you what they think is important for good information.

Time for a break? Display the group's ideas of what makes good information.

## Toolkit

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### Market place

Give the group time to look at some different types of information about health - leaflets, posters, demonstration packs, video clips (if possible). Make this a time where they can ask about things that interest or concern them. At the end find out what they liked about any of the information and what made it useful to them.

Again find a way to display their ideas.

### Find your way!

Set the scene. Everyone is in a hospital waiting room. Someone calls one of the group to an appointment. It is difficult to hear what is being said and the person has no idea where to go. Invite the group to act this out. How difficult can they make it to find out where to go? Now get the group to say how it could be done better. What methods and signs would be suitable for people with a range of different communication needs?

What have people's experiences been of trying to find out what is happening when they visit a surgery, clinic or hospital? How could this be improved?

Time for a break?

### Top marks!

Finish on a positive note. Let the group vote on the leaflet/video etc that they like best. Why should it get 'top marks'? Had anyone seen them before? Let people take away information that they find useful.

In the course of this session you will probably have found that there are some people who want to get more involved. Could any of them be asked to work with some of the services to help improve the information that is available to people with learning disabilities?

## Toolkit

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### Method: Stories

**Participants:** People with learning disabilities who use primary care services

**Topic:** Primary care responding to needs

**NHS QIS Quality Indicator Reference:** Statement 3.4

Primary care services are responsive to the needs of children and adults with learning disabilities and their family carers.

### Using stories of people's experiences

Stories can tell you a lot about how people are experiencing services. You can get groups to collect stories for you or you can suggest to people a way of sending them to you. If working with a group you may like to use a video as a trigger, for example, 'Just Ordinary People' available from NHS Education for Scotland or the SCLD Library. There are also video clips included on the CD which accompanies this guide.

If you ask for people's stories please find a way to show that you have listened to these, for example publishing them in a bulletin (with permission) or using them in training. And tell people what you are going to do with the stories you have heard. Remember to respect people's confidentiality. Don't use people's names in the story unless they have asked you to.

You could use a newspaper format as a way of inviting people's stories. An example follows. We also include some examples of how to map stories to the NHS QIS *Quality Indicators ~ Learning Disabilities* so that they can form part of the evidence base on service quality.

## Toolkit

### Sample format for story gathering

#### Stories Changed the Way We Work, Says Local Doctor

Dr. Bill Roberston has been a GP (family doctor) for 20 years. Last year his surgery decided to ask some patients to tell them what it was like to be a patient there. During Learning Disability week, one of the practice nurses asked some patients with learning disabilities what they liked about the surgery and what made it hard for them to use it.

The results were surprising. Dr Robertson found out that some people found it really hard to know why they were taking medicines and how much they should be taking. Now the practice



uses information sheets that are really easy to read. When a person with a learning disability gets a prescription the doctor puts a big cross on a diagram of the body to show what the medicine is for. The doctor also writes down very clearly how much of the medicine should be given, how it should be taken and when.

Jim, a patient at the surgery says, “I feel much happier now I know what the doctor is giving me. I can look at the information when I get home and talk to my support worker about it. If I have a question I now have more confidence to ask”.

### We need your help!

Do you have a story about the doctor or nurse at your local surgery? We want to hear about things that make it easier for you there. We also want to hear about things that make it difficult. Write to us or phone our hotline number. You can put your story on tape if you prefer.

Here are some questions to get you started...

#### My story

Think of a time when you needed the doctor.

How did you get to see them?

What happened when you went to the doctor?

Did you feel that the doctor listened to you?

Did you get the help you needed?

How did you feel after the visit? Did you know what was going to happen next?

What things help you when you go to the doctor?

What things are a problem?

## Toolkit

### Analysing stories and accounts

It is important to make the most of what people tell you. Below we illustrate how comments based on people's experiences could be mapped back to the indicator criteria in order to provide evidence for the quality indicators and improve standards.

*"One day it was this new doctor. She was very nice but she talked too fast. My head had really been hurting. I had to wait till my own doctor came back. I was really worried about what was happening."*

Does the practice have a way of identifying people with learning disabilities and their support needs? (*Quality Indicator Criterion 3.4.1*)

Are patient records/communication passports held? (*Quality Indicator Criterion 3.4.3*)

How are communication needs recognised and addressed? (*Quality Indicator Criterion 3.4.4*)

*"I dread going down to the surgery. My daughter gets very upset if she has to wait. One time she started making such a fuss that we just had to leave. I rang the chemist 'cos I knew she was poorly but I just couldn't risk her getting that upset in case she hit someone. I wish there was an easier way."*

Do the primary care service make flexible arrangements (appointments, home visits)? (*Quality Indicator Criterion 3.4.2*)

Is there capacity and competence within local services to understand and respond to the needs of children and adults with challenging behaviour? (*Quality Indicator Criterion 4.6.7*)

*"When she was due to go up to big school it was a stressful time for us as a family. We wanted so much to help her settle in. Would she make friends? It helped so much knowing that the school had a good picture of her health needs and that the arrangements were in place to make sure she would get the help that she needed."*

Are specific health needs identified and addressed in care plans? (*Quality Indicator Criterion 3.6.1*)

Is there continuity of healthcare through age-related transitions? (*Quality Indicator Criterion 4.2*)

Do health services support children and young people with learning disabilities attend mainstream schools? (*Quality Indicator Criterion 4.4.7*)

Are staff in educational settings trained/ supported by health staff? (*Quality Indicator Criterion 4.8.5*)

## Toolkit

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### Method: Interactive techniques

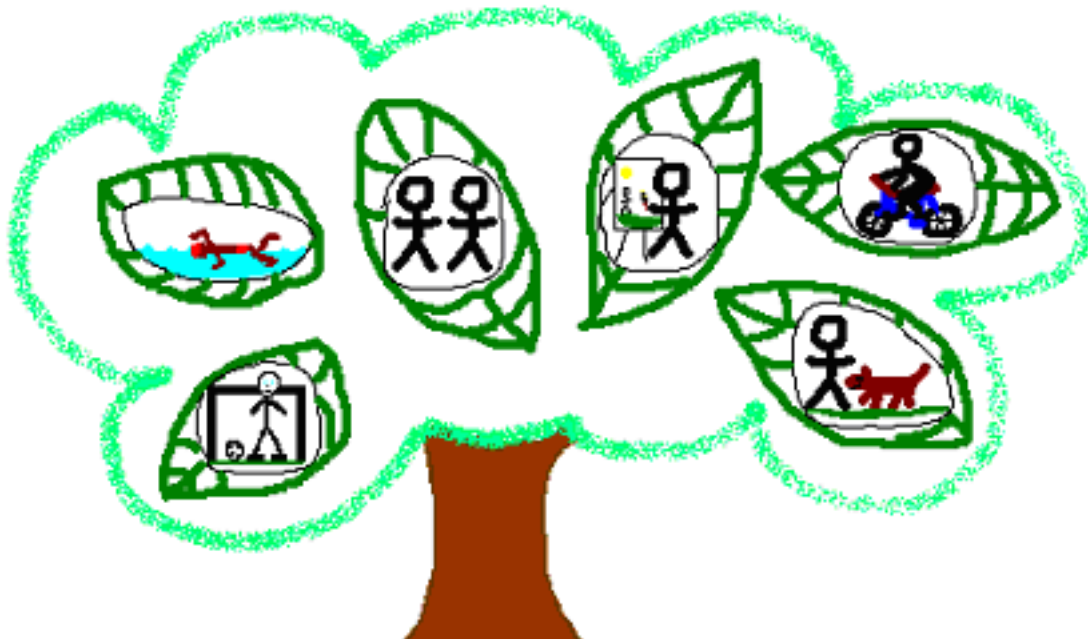
**Participants:** Children ('The healthy tree game' is for a group, 'I do stuff!' is for individuals)

**Topic:** Healthy life

### NHS QIS Quality Indicator Reference: Statement 2.5.6

There are opportunities for children and adults with learning disabilities to participate in activities which promote inclusion, social capacity and a healthy lifestyle.

### The healthy tree game



These exercises do not have to be done only with children with learning disabilities. It might be particularly informative to do them with a mixed group of children.

Make a tree out of sticks or draw one on a big piece of paper. Talk to the children about things that make them feel good. Have some pictures available of possible opportunities, eg swimming, being with friends. If possible make these relevant to that group of children. Ask which of these things actually happen for them.

Give the children time to choose or make a picture to attach to the tree. You could put these on card that is in the shape of a leaf. Give each child the support they need to take part.

Look at the tree and talk about the ways that all children could have these opportunities. What stops some from having the things they need to grow healthy lives?

## Toolkit

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### **‘I do stuff!’**

#### **Notes for facilitator**

This is an activity with an individual child to find out what opportunities they have to belong and lead a healthy life.

Ask someone who knows the child well to work with them to tell a simple story of what helps them to belong. Record the story by making a booklet using pictures, perhaps with words and symbols. In the course of making the booklet the child, and the person working with them, will be finding out together to what extent that child has opportunities to belong and live a healthy life.

You can develop the format in a way suitable for that child. Photographs, pictures or symbols can be used to make a record of the things and people that are significant. You might find it helpful to look at examples of communication passports. The child should be very actively involved in making their ‘I do stuff!’ book. PAMIS have developed multi-sensory stories for people with profound and multiple disability. See Useful organisations in Part 5.

## Toolkit

### I do stuff!

#### **This is a picture of me**

Show the child as an individual and how they look when they are happy and engaged.

#### **Here are some things I do that make me feel good**

Demonstrate the opportunities they have to promote their wellbeing.



#### **Here I am with some people I know**

Include an image of someone the child is close to. Does the child have opportunities to get to know and make friends with others, especially children?

#### **This is a place where I belong**

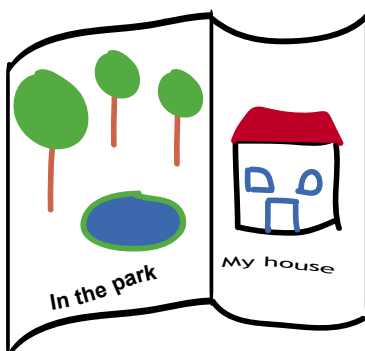
Does the child feel a part of any social settings they are in, eg at home, school and outside school?

#### **This is what helps me to join in**

Does the child get the specific support they need to be and feel included, eg a buddy or circle of friends and help with their health needs?

#### **This is a person who helps me to join in**

Are there any specific people who support the child to take up opportunities? It might be a parent, sibling, friend or particular worker. Maybe the family has a direct payment that enables them to have a support worker to assist the child to access specific opportunities.



#### **This is what I want to do more of**

Where is there scope to develop new opportunities?



## Toolkit

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### Method: Case study

### Participants: Planning stakeholders

### NHS QIS Quality Indicator Reference: Quality Indicator Criterion 6.4.9

There is evidence that the needs of adults with learning disabilities are taken into account within other strategies or plans such as mental health, older people and physical disability.

### Method

- 1 Identify relevant plans and key informants (stakeholders who know about each plan and can introduce you to other relevant people)
- 2 Interview key informants, finding out:
  - main priorities driving the plans
  - process by which the plans were developed
  - any joint links/planning forums
  - was anyone in learning disability services consulted?
- 3 Map the timescales for each plan
- 4 Establish and support a group of people with learning disabilities and family carers. Tell them the main points of each plan and get their views on what is missing.

Do the same with some key informants from learning disability health services.

### Case study content

Tell the story of what you have learned – explain how far the needs of people with learning disabilities are addressed in other plans.

Consider these other issues:

- priorities
- process
- timescales.

Try to use brief examples or quotes to illustrate the issues.

Present an overview of the plans comparing their content with priorities for people with learning disabilities and family carers. You could do this in a table.

Did you find any champions/good practice? Highlight these.

### Feedback and action

Send your case study to the key informants for comments. Produce some recommendations and present your findings at a strategic level. You may also want to bring the champions together to get some action!

# Resources

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## Relevant legislation

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### **Adults with Incapacity (Scotland) Act 2000**

The Adults with Incapacity (Scotland) Act 2000 provided ways to manage the financial and welfare affairs of people who are unable to manage them for themselves. The Act can be downloaded from: <http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2000/20000004.htm>

In addition the Scottish Executive has provided a site which offers information about the Act and how to use it. It is for both people with a personal interest and professionals, and contains background to the Act, application forms, information for staff and families as well as information on training.

The website address is:

<http://www.scotland.gov.uk/about/JD/CL/00016360/home.aspx>

### **Community Care and Health (Scotland) Act 2002**

The Community Care and Health (Scotland) Act 2002 introduced measures to improve care services in Scotland, including making care services free of charge. Part I defines what type of care accommodation can be charged for and allows for residential placements to be made outside of Scotland. The Act introduced new provisions to support carers.

The Act can be downloaded from:

<http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2002/20020005.htm>

### **Disability Discrimination Act 1995**

The Disability Discrimination Act (DDA) was passed in 1995 to end the discrimination that many disabled people face. It protects disabled people in:

- employment
- access to goods, facilities and services, including health services.
- the management, buying or renting of land or property
- education

The Act can be found at:

<http://www.legislation.hmso.gov.uk/acts/acts1995/1995050.htm>

Other useful legislation and Code of Practice can be found at this website:

<http://www.drc-gb.org/thelaw/index.asp>

### **Family Carers (Recognition and Services) Act 1995**

The Family Carers (Recognition and Services) Act 1995 established the entitlement of family carers to ask for an assessment. The Act can be found at:

[http://www.hmso.gov.uk/acts/acts1995/Ukpga\\_19950012\\_en\\_1.htm](http://www.hmso.gov.uk/acts/acts1995/Ukpga_19950012_en_1.htm)

### **Freedom of Information (Scotland) Act 2002**

The Freedom of Information (Scotland) Act 2002 introduces important new rights to access information held by public authorities or other organisations which provide services for them. The Act can be downloaded from:

<http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2002/20020013.htm>

The Scottish Executive has a website which offers information about the Act. The website address is:

<http://www.scotland.gov.uk/Topics/Government/FOI>

More information on the act and its implementation is available from the Scottish Information Officer's website. The Commissioner is a fully independent public official who has responsibility to promote and

## Relevant legislation continued

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enforce the Freedom of Information (FOI) legislation. The website address is:  
<http://www.itspublicknowledge.info/>

### **Human Rights Act 1998**

The Human Rights Act 1998 incorporates into UK law rights and freedoms guaranteed by the European Convention on Human Rights.

The Act can be downloaded from:  
<http://www.hmso.gov.uk/acts/acts1998/19980042.htm>

Information on Human Rights in Scotland is available in the report titled The European Convention on Human Rights, the Scotland Act and the Human Rights Act. It is available at:  
<http://www.scotland.gov.uk/library/documents-w9/huri-00.htm>

### **Mental Health (Care and Treatment) (Scotland) Act 2003**

This Act was passed by the Scottish Parliament in March 2003, this law comes into effect in **October 2005**. The Scottish Executive is working on a Code of Practice, and other guidance, to give people more detail about how the Act will work in practice.

The full Act is downloadable at:  
<http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003/20030013.htm>

An Information guide has been produced and can be downloaded at:  
<http://www.scotland.gov.uk/library5/health/nmha.pdf>

### **National Health Service Reform (Scotland) Act 2004**

The Act enables the dissolution of NHS Trusts and establishes Community Health Partnerships. Under the Act, NHS Boards and Special Health Boards have to develop effective regional planning of health services and to involve the public in this process. The Act also covers promotion of health improvement. The Act can be downloaded from:  
<http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2004/20040007.htm>

### **Protection of Children (Scotland) Act 2003**

This Act established new procedures for the creation of a List of those individuals unsuitable to work with children and young people. The Act can be downloaded from:  
<http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003/20030005.htm>

Further guidance and information can be found on the Scottish Executive Protection of Children website at:  
<http://www.scotland.gov.uk/about/ED/CnF/00017834/childprotection.aspx>

### **Race Relations Act (1976)**

The Race Relations Act provides protection from race discrimination in the fields of employment, education, training, housing, and the provision of goods, facilities and services. The Act can be downloaded from:  
<http://www.homeoffice.gov.uk/docs/racerel1.html>

### **Race Relations (Amendment) Act (2000)**

This Act amended the 1976 Act. It fulfilled recommendation 11 of the Stephen Lawrence Inquiry report and went further, prohibiting race discrimination in all public functions, with only a few limited exceptions. The Act can be downloaded from:

## Relevant legislation continued

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<http://www.hmsso.gov.uk/acts/acts2000/20000034.htm>

Both these Acts have significance for the delivery of health services and the involvement and participation of individuals in health care delivery.

### **Race Relations Act (1976) Amendment Regulations 2003**

Further changes and legislative requirements resulted from this Act. It implements the EC Article 13 Race Directive. The Act can be downloaded from:

<http://www.hmsso.gov.uk/si/si2003/20031626.htm>

Guidance on all of these acts can be found on both the Home Office website:

<http://www.homeoffice.gov.uk/docs2/rragidnce.html>

and that of the Commission for Racial Equality website:

<http://www.cre.gov.uk>

### **Regulation of Care (Scotland) Act 2001**

This legislation establishes a care regulation system through the registration and inspection of care services against national care standards. The Act can be downloaded from:

<http://www.scotland-legislation.hmsso.gov.uk/legislation/scotland/acts2001/20010008.htm>

### **Scotland Act 1998**

This legislation established the devolved Scottish Parliament whose remit includes health and community care. Section 5 provides a broad definition of equal opportunities. The Act can be downloaded from:

<http://www.hmsso.gov.uk/acts/acts1998/19980046.htm>

## Reports — general

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### **Adults with Learning Disabilities Implementation of 'The Same as You?' Statistics Release. Scottish Executive National Statistics publication.**

This Statistics Release presents the first national figures for services provided by local authorities in Scotland for adults with learning disabilities. The release can be downloaded from:

<http://www.scotland.gov.uk/stats/bulletins/00326.pdf>

### **A Map of Independent Advocacy across Scotland 2003-2004 edition.** (January 2004) Advocacy Safeguards Agency, Edinburgh.

The purpose of this report is to map out the current situation with regard to independent advocacy across Scotland. This includes a description of individual advocacy, the level, source and security of their funding, and committed developments to March 2004. The report can be downloaded from:

<http://www.scotland.gov.uk/library5/justice/amoi.pdf>

### **Autistic Spectrum Disorders Needs Assessment Report (2001). Public Health Institute for Scotland.**

This report recommends how services can be improved and, in particular, establishes the need for quicker access to assessment and diagnosis.

<http://www.scotland.gov.uk/Topics/Health/care/18950/15906>

**Becoming Visible. (2004) Lisa Curtice.** A CD-ROM and accompanying resource pack, produced by Common Knowledge in collaboration with PAMIS and SCLD. It tells the stories of three people with profound and multiple learning disabilities and the issues they face: growing up, public attitudes and being included.

Available soon. See Common Knowledge's websites for details:

<http://www.ckglasgow.org.uk>

<http://www.sclld.org.uk>

<http://www.dundee.ac.uk/pamis>

### **Community Care: A Joint Future.** (November 2000) Scottish Executive.

This contains the main report of the Joint Future Group. The main aim of the Group is to find ways to improve joint working in order to deliver modern and effective person-centred services. The report can be downloaded from:

<http://www.scotland.gov.uk/library3/social/rjfg-00.asp>

The Joint Future website can be accessed at:

<http://www.scotland.gov.uk/about/HD/CCD2/00017673/Home.aspx>

### **For Scotland's Children report: better integrated services.** (2001) Scottish Executive. ISBN: 07559 0306 4.

This report has an Action Plan which contains a range of ways in which local authorities, the NHS and the voluntary sector can work together to create a single children's services system, backed up by a number of good practice examples. They look at the statutory and voluntary sectors to use this as a focus for developing better integrated children's services.

The report is available at:

<http://www.scotland.gov.uk/library3/education/fcsr-00.asp>



## Reports — general continued

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**Investigations into Scottish Borders Council and NHS Borders Services for People with Learning Disabilities: Joint Statement from the Mental Welfare Commission and the Social Work Services Inspectorate.** (April 2004) Social Work Services Inspectorate, Scottish Executive. ISBN: 0 7559 1054 0.

You can download this report at:

<http://www.scotland.gov.uk/library5/social/swsisbpds.pdf>

**Modernising Government Fund: Round 1: Final Report.** (2003) Scottish Executive.

The Modernising Government Fund (MGF) is part of the 21st Century Government plan. Its purpose is to support innovation in the public sector, to address policy priorities for modernisation and particularly to support and promote joined-up working.

The report is available at:

<http://www.scotland.gov.uk/library5/government/osmgfr1r-00.asp>

**No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse.** (2000) Department of Health.

Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse.

The report is available to download from:

<http://www.dh.gov.uk/assetRoot/04/07/45/40/04074540.pdf>

**On the Borderline? People with learning disabilities and/or autistic spectrum disorders in secure, forensic and other specialist settings.** (2004) Scottish Executive.

The document is available to download from:

<http://www.scotland.gov.uk/library5/education/otb-00.asp>

**Partnership in Practice Agreements (PiPS)**

Further information about PiPs can be obtained at:

<http://www.scotland.gov.uk/about/HD/CCD/00015680/PiPs.aspx>

and at:

<http://www.sclد.org.uk/doc.pl?file=i%2011.doc>

**Report of the Inspection of Scottish Borders Council Social Work Services for People Affected by Learning Disabilities.** (April 2004) Social Work Services Inspectorate, Scottish Executive. ISBN: 0 7559 4185 3.

You can download this report at:

<http://www.scotland.gov.uk/library5/social/bcpald.pdf>

**Research Governance Framework for Health and Community Care.** (2001) Chief Scientist Office

This document sets standards and details responsibilities for the good conduct of research.

You can find the report at:

<http://www.scotland.gov.uk/HD/CSO/00016877/resgovernance.aspx>

## Reports — general continued

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**The same as you? A review of services for people with learning disabilities.** (2000) Scottish Executive.

This review looks at services, especially in social and healthcare, and their relationship with education, housing, employment and other areas as well as people's lifestyles. It says that people with learning disabilities should be able to lead normal lives. You can download this report at: <http://www.scotland.gov.uk/Resource/Doc/1095/0001661.pdf>

**Service for All - Making it Happen.** (2003) SHS Trust. ISBN: 1 899751 30 0.

A report from the Service for All conference held on 18<sup>th</sup> June 2003 in Edinburgh. This is a report on the conference that brought together people with disabilities, people with mental health problems, older people and their families and staff in the NHS who are working to make services more accessible. The report can be downloaded from: <http://www.shstrust.org.uk/pdf/servicesforall1.pdf>

**Standards for disability information and advice provision in Scotland.** (Revised 2004) Scottish Accessible Information Forum. ISBN: 0 9546 7001 9.

The standards were produced to assist agencies in the voluntary, private and statutory sectors and to ensure that disabled people can access effective information and advice services. This can be downloaded at: [http://www.saifscotland.org.uk/publications/rev\\_stdrd/revised\\_standards.pdf](http://www.saifscotland.org.uk/publications/rev_stdrd/revised_standards.pdf)

**The Strategy for Carers in Scotland.** (1999) Scottish Executive

This sets out the action the Executive will take to develop more flexible, local services, develop national standards, monitoring, legislation, better and more targeted information and address the specific needs of young carers. This can be downloaded at: <http://www.scotland.gov.uk/library2/doc10/carersstrategy.asp?textonly=true>

**Working for a Change? The same as you? National Implementation Group. Report of the short-life working group on Employment.** (2003) Scottish Executive.

The report says that most people with a learning disability want to work, and the evidence shows that they get the same satisfaction from working as anyone else. Most want employment in ordinary jobs. Some people with a learning disability want to set up their own business, and could do this with support. But in Scotland it is estimated that only one adult in 20 with learning disabilities has any form of paid work. It gives recommendations on how to try to change this.

The report is available to download from: <http://194.247.95.101/library5/health/wcsy.pdf>

The Easy Read summary is downloadable at: <http://194.247.95.101/library5/health/sayers.pdf>

**Working Together: Co-operation between government and faith communities. Recommendations of the Steering Group reviewing patterns of engagement between Government and Faith Communities in England.** (2004) Home Office Faith Communities Unit.

A report on the Review commissioned by the Government to look at best practice and consultation based on the recommendations of the Steering Group.

The report is available to download from: [http://www.homeoffice.gov.uk/docs3/workingtog\\_faith040329.pdf](http://www.homeoffice.gov.uk/docs3/workingtog_faith040329.pdf)

## Reports — communication

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**Communicating with Pictures and Symbols Proceedings of Augmentative Communication in Practice: Scotland 2003.** (2003) A. Wilson. (editor). CALL Centre. ISBN: 1898042 25 X.

See the CALL centre website: <http://www.callcentrescotland.org.uk> for details on how to obtain this.

**Exploring your Emotions Manual.** (1998) A. Holland, A. Payne and L. Vickery. BILD. ISBN: 1 902519 00 0.

This pack is designed to be a versatile set of photographs for use with adults with learning disabilities and for people with other disabilities. The photographs show people demonstrating an emotional state or in a situation likely to evoke an emotional response. They can be used in a variety of ways: to enable exploration; expression and development of emotional understanding to life experiences; to support the development of language for emotions; and as a tool in the development of a therapeutic relationship.

You can order this from the BILD website: <http://www.bild.org.uk/publications/index.htm>

Orders may also be placed by telephone, fax or post from BILD, BookSource, 32 Finlas Street, Cowlares Estate, Glasgow G22 5DU. Telephone BookSource on 08702 402 182 with the book name and ISBN number.

**Personal Communication Passports; Guidelines for Good Practice** (2003) Sally Millar and Stuart Aitken. (2003) CALL Centre. ISBN: 1 898042 21 7.

This is a comprehensive guide to analysing and using passports, which are person-centred way of recording key information about a person and their way of communication.

See the CALL centre website: <http://www.callcentrescotland.org.uk> for details on how to obtain this.

**See What I Mean: guidelines to aid understanding of communication by people with severe and profound learning disabilities.** N. Grove, K. Bunning, J. Porter and M. Morgan. (2000) BILD. ISBN: 1 9021519 41 8.

A detailed account of how to check differing interpretations, with prompts for key questions, when and when not to use a structured discussion and very useful examples and photocopiable checklists

You can order this from the BILD website: <http://www.bild.org.uk/publications/index.htm>

**Talking Mats™ and Learning Disability.** (2002 and several publications) J. Murphy and L. Cameron

Talking Mats is a visual framework that uses picture symbols to help people with communication difficulty to express their views more easily.

From: AAC Research Unit, Dept. of Psychology,  
University of Stirling  
Stirling, FK9 4LA,  
Tel: 01786 467645  
Email: [aacscotland@stir.ac.uk](mailto:aacscotland@stir.ac.uk)  
Website: <http://www.aacscotland.com>

## Reports — equality

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**Equality and Diversity Impact Assessment Toolkit.** (February 2005) NHS Scotland, Scottish Executive. ISBN: 0 7559 4513 1.

The purpose of the toolkit is to improve the way in which the Scottish Executive Health Department (SEHD) and NHS Boards develop their policies and services by ensuring that they reflect the current equality and diversity legislative framework. The toolkit can be downloaded from:  
<http://www.scotland.gov.uk/library5/health/eqdiat-00.asp>

**Equality and Human Rights in the 21st Century: The Scottish context.** (June 2004) Forum on Discrimination.

This is a briefing paper prepared by the Scottish Council for Voluntary Organisations (SCVO) and the Scottish Forum to provide information on the changing legal and institutional landscape of equalities and human rights; to signpost to other sources of information, support and advice; and to encourage responses to the current UK Government consultation on the creation of a Commission for Equalities and Human Rights (CEHR). The paper can be downloaded from:  
[http://www.civicforum.org.uk/briefing/briefing\\_pdf/old/040701\\_equalities.pdf](http://www.civicforum.org.uk/briefing/briefing_pdf/old/040701_equalities.pdf)

**Equality Strategy: Working Together for Equality** (2000) Scottish Executive

The Scottish Executive's strategy to tackle discrimination and disadvantage and increase respect for diversity in Scotland. It is available to download from:  
<http://www.scotland.gov.uk/library3/socialwterm-00.asp>

**Fair for All: everyone is entitled to fair access to health – this is the founding principle of the NHS: Improving the Health of Ethnic Minority Groups and the Wider Community in Scotland.** (December 2001) NHS Scotland, Scottish Executive.

The Fair for All Report addresses problems of access to and use of the NHS which are often faced by people from minority ethnic backgrounds. It deals with issues such as culturally sensitive ways of communicating, the provision of religiously appropriate food, and the translation of patient information. It also shows examples and models of good practice in relation to involvement and participation of minority ethnic community members. It can be found on the Scottish Executive website at:  
<http://www.scotland.gov.uk/library3/society/ffar-00.asp>

A copy of the **Guidance Leaflet** is available at:  
<http://www.scotland.gov.uk/library3/society/ffal-00.asp>

**Fair Enough? Fair For All Progress Report: Analysis of Race Equality Schemes and Fair for All Action Plans.** (November 2003) Scottish Executive.

This report reviews the progress of Fair for All, together with local equality schemes and action plans. It contains limited information on minority ethnic individuals who have learning disabilities. The report is available at:  
<http://www.scotland.gov.uk/library5/justice/feffap-00.asp>

**Fairness for All: A new commission for Equality and Human Rights.** (2004) Department of Trade and Industry (DTI).

A White paper from the DTI which announced the development of the Commission for Equality and Human Rights (CEHR). The paper details its role, duties and powers. The paper can be downloaded from:  
<http://www.dti.gov.uk/access/equalitywhitepaper.pdf>

## Reports — equality continued

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**Social Justice: A Scotland where everyone matters.** (1999) Scottish Executive.

This document gives Scotland a set of targets against which to measure progress year by year through an Annual Scottish Social Justice Report. It is available at:  
<http://www.scotland.gov.uk/library2/doc07/sjmd-00.htm>

## Reports — health

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**Cancer and People with Learning Disabilities: The Evidence from Published Studies and Experiences from Cancer Services.** (2001) James Hogg, John Northfield and John Turnbull. British Institute of Learning Disabilities (BILD). ISBN: 1 902519 73.

Cancer is a key health issue but we know very little about cancer in people with learning disabilities. This BILD report was commissioned by the Department of Health. Part one provides a comprehensive overview of the scientific literature. Part two includes the views of people who plan and commission cancer services, as well as health care practitioners. Together they provide an important review of current knowledge and practice.

You can order this from the BILD website: <http://www.bild.org.uk/publications/index.htm>

Orders may also be placed by telephone, fax or post from BILD, BookSource, 32 Finlas Street, Cowlares Estate, Glasgow G22 5DU. Telephone BookSource on 08702 402 182 with the book name and ISBN number.

**Community Health Partnerships: Improving the Health and Wellbeing of People with Learning Disability and/ or Autistic Spectrum Disorder.** (December 2004) Scottish Executive.

The Advice Note is intended to inform the development of local arrangements to deliver the policy objectives of Community Health Partnerships (CHPs) and Joint Future in relation to services for people with learning disabilities and/ or ASD. It supports the aims and expected service outcomes set out in the CHP statutory guidance.

You can download this from the Community Health Partnerships website:  
<http://www.show.scot.nhs.uk/sehd/chp/CHPAdvicefinalLDAS201205.pdf>

**Do not attempt resuscitation: Decisions and disability in Scotland.** (2004) Sheila Riddell, Charlotte Pearson and Nick Watrson. Disability Rights Commission.

A study on policy and practice into the resuscitation of disabled patients and their rights. The report is available on the DRC website:  
[www.drc-gb.org.uk](http://www.drc-gb.org.uk)

**Down Syndrome and Dementia Resource Pack.** (2003) Karen Todd, Vicky Turk, and Michelle Christmas. BILD. ISBN: 1 904082 37 8.

A resource for family carers, staff and other professionals supporting people with Down's Syndrome, to help them with practical day to day issues.

You can order this from the BILD website: <http://www.bild.org.uk/publications/index.htm>

Orders may also be placed by telephone, fax or post from BILD, BookSource, 32 Finlas Street, Cowlares Estate, Glasgow G22 5DU. Telephone BookSource on 08702 402 182 with the book name and ISBN number.

**Dying Matters - A workbook on caring for people with learning disabilities who are terminally ill.** (Due for publication 2005) Foundation for People with Learning Disabilities. ISBN: 1 903645 56 5.

This manual has been written for support staff and managers in learning disabilities services to help them address the needs of people with learning disabilities who are dying, and to explore their role in providing care and support. It will assist staff and managers to talk together about how to manage a death in their service and/or to plan ahead for this eventuality. It will also provide a guide to the roles of healthcare professionals and how best to communicate and work with them in the best interests of the dying person.

## Reports — health continued

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It will be available to download from the Foundation for People with Learning Disabilities website: <http://www.mhf.org.uk>. Mental Health Foundation Publications Department, tel. +44 (0)20 7803 1100 or email: [books@mhf.org.uk](mailto:books@mhf.org.uk).

**Getting it right together: the implementation of recommendations 16, 17 and 20 from ‘Promoting Health, Supporting Inclusion’.** (2004) Elaine Kwaitek. NHS Education for Scotland.

This report outlines the processes and outcomes of a project undertaken by NHS Education for Scotland to examine how the educational input regarding the health needs of people with a learning disability can be strengthened within all nursing programmes.

Website: <http://www.nes.scot.nhs.uk>

**Health Care and the Autism Spectrum: a guide for health professionals, parents and carers.** (2004) Alison Morton-Cooper. Jessica Kingsley Publishers. ISBN: 1 85302 963 7.

Communication difficulties, sensory overload and extreme discomfort with physical contact are all traits common in autism that make basic patient care and routine medical procedures extremely difficult. The book deals with the ethical issues as well as the practical challenges that everyone involved has to deal with.

To order, go to the Jessica Kingsley Publishers website: <http://www.jkp.com> You can then send your order to them through a secure server, or print off the page and fax or post it to them. Alternatively, you can contact them direct by phone or fax to place your order. Tel: +44 (020) 7833 2307 Fax: +44 (020) 7837 2917.

**Health Needs Report: People with Learning Disabilities in Scotland Health Scotland.** (February 2004) NHS Health Scotland, Scottish Executive. ISBN: 1 8448 5109 5.

A summary version of the Learning Disability Health Needs Assessment can be found on the PHIS website at:

<http://www.phis.org.uk/pdf.pl?file=pdf/LDSummary.pdf>

For a copy of the full report mail to : [info@phis.org.uk](mailto:info@phis.org.uk)

**Home at last? The same as you? National Implementation Group. Report of the short-life working group on Hospital Closure and Service Reprovision.** (2003) Scottish Executive.

The report can be downloaded from:

<http://194.247.95.101/library5/health/hal.pdf>

The Easy Read summary is downloadable at:

<http://194.247.95.101/library5/health/hals.pdf>

**Improving disabled people’s access to health provision.** (September 2003) SHS Trust. ISBN: 1 899751 29 7.

A report of a conference considering the demands and challenges of changing policy and legislation, in particular the Disability Discrimination Act 1995, held by the Disability Rights Commission, NHS Quality Improvement Scotland, the Scottish Executive and Scottish Human Services Trust. The report can be downloaded from:

<http://www.shstrust.org.uk/pdf/drcreport1.pdf>



## Reports — health continued

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**Informing Patients; an assessment of the quality of patient information materials.** (1998) Angela Coulter, Vikki Entwistle, and David Gilbert. King's Fund. ISBN: 1 8571 7214 0.

This is a manual examining what information materials patients prefer and how well currently available materials meet their needs. The manual makes useful and generally applicable recommendations for the development of good quality patient information sources. It is an excellent guide to the process of development and appropriate content of patient information materials. This can be ordered from: <http://www.kingsfund.org.uk> or by mail order form, phone +44 (0)20 7307 2591 for more information.

**It's Your Move: Down's Syndrome and Dementia.** Down's Syndrome Scotland.

A health information guide for GPs to plan a strategy that will ensure the right intervention, and diagnosis, at the right time for people with Down's Syndrome and dementia. The guide can be downloaded from:

<http://www.dsscotland.org.uk/publications/professionals-students/its-your-move.pdf>

**NHS Code of Practice on Protecting Patient Confidentiality.** (2003) NHS Scotland, Scottish Executive. ISBN: 0 7559 0875 9.

This Code of Practice details the standards and best practice indicators within which health professionals are expected to work and undertake consultation and/or participation exercises. The document can be downloaded from:

<http://www.show.scot.nhs.uk/confidentiality/publications/6074NHSCode.pdf>

**NHS Quality Improvement Scotland, Quality Indicators ~ Learning Disabilities.** (2004) NHS Quality Improvement Scotland. ISBN: 1 84404 257 X.

A full text version can be downloaded at:

<http://www.nhshealthquality.org/nhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf>

An Easy Read Summary version is available at:

<http://www.nhshealthquality.org/nhsqis/files/Easy%20Read%20Summary%20Learning%20Disability%20Quality%20Indicators.pdf>

**Once a day one or more people with learning disabilities are likely to be in contact with your primary healthcare team. How can you help them?** (1999) Department of Health.

A handbook which aims to promote good practice in enabling people with learning disabilities to access and receive good quality services from primary health care teams. Its objective is to address the problems caused by the fact that there are often difficulties in meeting the needs of people with learning disabilities. The handbook can be downloaded from:

<http://www.dh.gov.uk/assetRoot/04/04/27/79/04042779.pdf>

**Our National Health: a Plan for Action, a Plan for Change.** (January 2001) Scottish Executive Health Department.

This document evidenced the Scottish Executive commitment to improving health, reducing inequality and increasing public involvement in the Health Service.

The report can be downloaded from:

<http://www.scotland.gov.uk/library3/health/onh-00.asp>



## Reports — health continued

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**Palliative Care and Learning Disabilities: A report from a one day conference on 11<sup>th</sup> February 2003 to examine and reflect on the issues of palliative care and its provision for people with learning disabilities.** (2003) SHS Trust. ISBN: 1 8997 5123 8.

A report on national conference between health professionals and learning disability colleagues.

**Partnership for Care: Scotland's Health White Paper.** (February 2003) NHS Scotland, Scottish Executive. ISBN: 0 7559 0688 8.

Setting out the Scottish Executive's policy on health, this document seeks to put the patient at the centre, making them key drivers of change, and a fundamental source of the definition of quality and the development of patient-centered services. The document can be downloaded from:

<http://www.scotland.gov.uk/library5/health/pfcs-00.asp>

A patient leaflet is available at: <http://www.scotland.gov.uk/library5/health/hwpl.pdf>

*Community Health Partnerships* were a key element within Partnership for Care. Information on their developing role and models of good practice can be found at the Community Health Partnership Development Group (CHPDG) webpage:

<http://www.show.scot.nhs.uk/sehd/chpdg/>

**Promoting Health, Supporting Inclusion: the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities.** (2002) NHS Scotland Scottish Executive

Charts the way forward for responsive nursing services including recommendations that people with learning disabilities and family carers should be involved in training nurses. The report can be downloaded from:

<http://www.scotland.gov.uk/library5/health/phsi.pdf>

**Promoting Health, Supporting Inclusion. Healthy lives, part of the community: How nurses and midwives can support children and adults with learning disabilities and their families.** (July 2002) NHS Scotland, Scottish Executive, Scottish Consortium for Learning Disability, FAIR Multimedia.

An Easy Read version which is available at:

<http://www.scotland.gov.uk/library5/health/phsin-00.asp>

NHS Education for Scotland (NES) runs an online forum on **Promoting Health Supporting Inclusion** which can be accessed at:

<http://www.nes.scot.nhs.uk/nursing/PHSI/>

**Protecting Patient Confidentiality: Final report.** (2002) The Confidentiality & Security Advisory Group for Scotland.

This report from the Confidentiality and Security Advisory group for Scotland aims to provide advice on the confidentiality and security of health related information to the Scottish Executive, and to the public and health care professionals. The report raises important issues both on confidentiality during consultation and on data protection. The report can be downloaded from:

<http://www.show.scot.nhs.uk/sehd/publications/ppcr/ppcr-00.htm>

## Reports — health continued

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### **Report from the Health Champions Project.** (2004) Health Champions Project.

The Health Champions Project began as a Partners in Change initiative. It brought together families of people who had learning disabilities and staff who worked in a range of NHS settings. The report talks about what the project did.

Available from Outside the Box Development Support, Glasgow.

Website: [www.otbds.org](http://www.otbds.org)

### **Research Ethics.** (2001) Chief Scientist Office

Any research involving NHS patients, service users, care professionals or volunteers or their data must have approval from an NHS Research Ethics Committee before it can begin. Everyone involved in research has a responsibility to protect the dignity, rights, safety and wellbeing of actual and potential research subjects.

See: <http://www.scotland.gov.uk/about/HD/CSO/0616877/ethics.aspx>

### **Scottish Executive Review of Speech and Language Therapy, Physiotherapy and Occupational Therapy for Children and Speech and Language Therapy for Adults with Learning disabilities and Autistic Spectrum Disorder.** (2003) NHS Scotland, Scottish Executive

A review of the availability of services. This document is available from:

<http://www.scotland.gov.uk/library5/health/rsltm-00.asp>

### **Treat Me Right: Better healthcare for people with a learning disability.** (2004) Mencap.

Treat me right is a campaign for better healthcare for people with a learning disability. This is a report about health of people with learning disabilities and their experiences of healthcare services in England and Northern Ireland. It also has recommendations from the report's findings.

It is available to download from:

[http://www.mencap.org.uk/download/treat\\_right.pdf](http://www.mencap.org.uk/download/treat_right.pdf)

There is an Easy Read summary available to download from:

[http://www.mencap.org.uk/download/treat\\_right\\_acc.pdf](http://www.mencap.org.uk/download/treat_right_acc.pdf)

## Reports — involving children and young people

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### **All Join In.** (2004) Triangle/NSPCC

A video of children, looking at new experiences and new relationships through a child's eyes. This unique video, made with a diverse group of 3-7 year olds, helps children develop skills for communicating and making friends and for understanding their own and others feelings.

Available from:

Triangle  
Unit 310  
91 Western Road  
Brighton  
East Sussex  
BN1 2NW.

Website: <http://www.triangle-services.co.uk>

### **Children are Service Users Too: A guide for consulting children and young people. Revised edition.** (2004) Save the Children. ISBN: 1 84187 086 2.

This practical guide offers support to all organisations looking to consult children and young people. It's an ideal starting point for those new to consulting children and young people, with check lists and question and answer sections to help you get started. It can be used to draw up a strategy for consulting children and young people and to ensure that issues of representation and child safety have been considered.

Available from:

<http://www.nbninternational.com/>

### **Children in Scotland – How to (principles)**

See this section of the Children in Scotland website for principles and good practice on participation.

Website: [http://www.childreninscotland.org.uk/html/par\\_mak.htm](http://www.childreninscotland.org.uk/html/par_mak.htm)

### **Listening on All Channels: Consulting with disabled children and young people.** (1999) R.

Marchant, M. Jones, A. Julyan and A. Giles.

Available from:

Triangle  
Unit 310  
91 Western Road  
Brighton  
East Sussex  
BN1 2NW.

Website: <http://www.triangle-services.co.uk>

### **Listening to Children with Communication Support Needs** (2002) Stuart Aitken and Sally Millar. ISBN: 1 898042 20 3.

A pack that provides many resources and detailed guidelines to guide the choice of appropriate techniques for communication and consultation (Most of these are equally valid for adults).

Available from the CALL Centre, see their website:

[http://callcentre.education.ed.ac.uk/About\\_CALL/Publications\\_CAA/publications\\_caa.html](http://callcentre.education.ed.ac.uk/About_CALL/Publications_CAA/publications_caa.html)

## Reports — involving children and young people

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**Listening to Children 2004.** (2004) Stuart Aitken and Sally Millar. ISBN 1 898042 26 8.

This new pack includes practical materials for anyone who wants to listen to and find out the views of children who have communication disabilities. Teachers, therapists, social workers and care workers in local authorities, health boards, voluntary organisations and other agencies will find the book and accompanying CD a valuable resource to use in their practice. Policy makers and managers in education, health and social work services will find guidance on how to embed involvement, participation and consultation in everyday practice across services.

Available from the CALL Centre, see their website:

[http://callcentre.education.ed.ac.uk/About\\_CALL/Publications\\_CAA/publications\\_caa.html](http://callcentre.education.ed.ac.uk/About_CALL/Publications_CAA/publications_caa.html)

**Listen Up - Helping children with a learning disability complain about the services they use.**

This pack is for anyone working with children and young people (5-19 years) with learning disabilities, including those with additional needs.

It provides a toolkit of resources for supporting children to speak up and for preparing adults to listen to them. It includes children's workbooks, a CD-Rom with templates of materials that can be customised, the Dragon board game, a staff training video and a staff workbook with full guidance on using the resources.

The pack is available from:

Mencap  
123 Golders Lane  
London  
EC1Y 0RT  
Tel: 020 7454 0454

or on loan from the SCLD library.

Tel: 0141 418 5420.

Website: [www.mencap.org.uk/listenup](http://www.mencap.org.uk/listenup)

**Making it Work for Scotland's Children: Child Health Support Group Overview Report 2003.**

(October 2003) Scottish Executive. ISBN: 0 7559 0840 6.

A national report on children's health and good practice. This group is also examining the nature of consultation and the participation of children and young people. The report can be downloaded from: <http://www.scotland.gov.uk/library5/health/mwsc.pdf>

**Never Too Young: How young children can take responsibility and make decisions.** (2003)

Save the Children. ISBN: 1 84187 075 7.

A practical resource that shows how young children can participate, make decisions and take responsibility for their actions. It provides staff with information about why participation works, and explores tried and tested techniques for involving children in decisions that affect them. It also relates to the experience of children with additional support needs.

Available from:

<http://www.nbninternational.com/>

## Reports — involving children and young people

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**Participation - Spice It Up!: Practical Tools for engaging children and young people in planning and consultations.** (2001) Save the Children. ISBN: 1 84187 062 5.

Packed full of practical tools and ideas for engaging children and young people, Participation - Spice It Up! is serious fun and a fun way to deal with serious issues.

Participation - Spice It Up! looks at the ideas and values that underlie our approach to participation. There are also top tips on the practicalities and pitfalls of planning and running collaborative and creative sessions.

The main course of the book consists of over 40 tried and tested activities you can mix and match. Of particular use to professionals and organisations who work with children and young people for example local authority workers, school teachers, play workers, youth workers, care workers, health professionals.

Available from:

<http://www.nbninternational.com/>

**Re:action: Consultation Toolkit.** (2001) Save the Children, Edinburgh. ISBN: 1 84187 040 4

This is a practical guide about how to consult with children and young people on policy-related issues. It is written for community workers, youth workers, teachers, local authority workers, health workers, facilitators and other organisations and individuals working with children and young people. It is also for children and young people themselves who may be involved or interested in organising a consultation exercise.

The publication is available from Save the Children in Scotland. The price is available on application. Please contact Joyce Sperber for details on 0131 527 8200.

7th Floor

Haymarket House

8 Clifton Terrace

Edinburgh

EH12 5DR

Tel: 0131 527 8200

Fax: 0131 527 8201

e-mail: [Scotland@scfuk.org.uk](mailto:Scotland@scfuk.org.uk)

Alternatively it can be downloaded free of charge at:

[http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/960\\_reactiontoolkit.pdf](http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/960_reactiontoolkit.pdf)

**Starting With Choice Inclusive strategies for consulting young children.** (2004) Save the Children. ISBN: 1 84187 085 4.

Starting with Choice provides early years workers with clear, practical guidance on consulting young children, and a range of techniques that help young children, including those with disabilities, to express their views and make choices. It also looks at when consultation can be effective, how it fits in to the foundation stage guidance, and how to train and support early years workers to gain the skills they need.

This guide shows that innovative and exciting solutions can be found so that all children can participate in group decision-making.

Available from:

<http://www.nbninternational.com/>

## Reports — involving family carers

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**Family Matters: Counting Families In.** (2001) C. Ward, Department of Health.

This excellent report is based on consultations with family carers and aims to support the implementation of the Valuing People strategy by explaining how to make a difference to the lives of family carers. It is available on the website:

<http://www.dh.gov.uk/assetRoot/04/01/46/10/04014610.pdf>

**PAMIS (Promoting a More Inclusive Society)**

PAMIS works with families caring for a child or adult with profound and multiple learning disabilities and offers information, training and support. It also runs the PMLD network for people interested in sharing ideas and information.

Website: <http://www.dundee.ac.uk/pamis>

## Reports — public involvement

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### **Building Strong Foundations toolkit**

The Involving People Team has produced an excellent pack on involving people in the NHS. Called 'Building Strong Foundations', it was collaboration between NHS Scotland, the Scottish Executive and Partners in Change. The "toolkit" is a guide to some of the approaches available to facilitate the involvement of people. The approaches are not only health related but generic in their use although they are becoming more widely used within the Health Service with a view to engaging the public in decision-making for the future of the Health Service.

Website: <http://www.show.scot.nhs.uk/involvingpeople>

### **A New Public Involvement Structure for NHS Scotland: Patient Focus and Public Involvement: a draft for consultation.** (March 2003) NHS Scotland, Scottish Executive.

This consultation document details proposals for new public involvement structures within the NHS in Scotland, especially the creation of a Scottish Health Council. The document can be downloaded from:

<http://www.scotland.gov.uk/library5/health/npis.pdf>

### **Patient Focus, Public Involvement.** (December 2001) NHS Scotland, Scottish Executive.

This document sought to provide a framework for delivering a culture change in the NHS where patient-focus is at the heart of service design and delivery.

Full details of the approach that NHS QIS will take to securing an effective partnership with the public are set out on this webpage:

<http://www.scotland.gov.uk/library3/health/pfpi-00.asp>

### **Route map to user and carer participation.** (2001) Scottish Development Centre for Mental Health.

The Route Map is for people who use services or their friends and families. The Route Map provides a way of reviewing how well organisations and services involve people from the perspective of users and carers. Available from their website:

<http://www.sdcmh.org.uk/pdf/route%20map%20part%20one.pdf>

## Reports — sexuality

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**‘Batteries Not Included’- an exploration of issues in sex education and sexuality for people with multiple disorders.**

Details on putting together a policy as well as a list of references and additional resources are available on Scottish Sensory website at:

<http://www.ssc.mhie.ac.uk/courses/battery7.html>

**Making Choices, Keeping safe: Policy and Practice Guidelines on relationships and sexual wellbeing when working with people with learning disabilities.** (2004) NHS Lothian.

This policy and its associated guidelines have been produced as a response to the sexual health needs of people with learning disabilities. It was written in wide consultation with, and with input from, people with learning disabilities, their parents and carers. It is a supporting document to the Edinburgh and the Lothians sexual health strategy. The report can be downloaded from:

[http://www.mcks.scot.nhs.uk/resources/Making\\_Choices\\_April\\_2004.pdf](http://www.mcks.scot.nhs.uk/resources/Making_Choices_April_2004.pdf)



## Useful organisations

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### **21<sup>st</sup> Century Social Work Review**

The 21st Century Social Work Review is looking to shape the future of social work services for the next 20 years. It includes the role of the social worker and social work in the 21st century as well as the delivery of integrated services, quality assurance frameworks, the leadership and management of the profession, the capacity of the social work profession and the legislative framework involved.

Website: <http://www.21csocialwork.org.uk/remit.html>

### **Advocacy Safeguards Agency (ASA)**

ASA seeks to support commissioners of services to develop independent advocacy; to evaluate existing independent advocacy organisations; to ensure independent advocacy is part of national policy developments, and to research the impact of independent advocacy. They produce a directory: A Map of Independent Advocacy Across Scotland.

Website: <http://www.advocacysafeguards.org>

### **Association for Real Change (ARC) Scotland**

ARC Scotland is based in Edinburgh. It is an umbrella organisation which brings together those who provide services for people with learning disabilities.

ARC UK has a National Ethnicity and Learning Disability Network funded by the Department of Health to develop links and share good practice.

Contact Pam Smith for more details: [pam.smith@arcuk.org.uk](mailto:pam.smith@arcuk.org.uk)

Website: <http://www.arcuk.org.uk>

### **British Institute of Learning Disabilities (BILD)**

The British Institute of Learning Disabilities is based in Kidderminster. It has many people from different work backgrounds providing services to improve their quality of life for all people with a learning disability.

Website: <http://www.bild.org.uk>

### **Capability Scotland**

Based in Edinburgh, Capability Scotland is Scotland's largest disability organisation providing a range of services to adults and children with disabilities.

Website: <http://www.capability-scotland.org.uk/>

### **Care 21: care for the 21<sup>st</sup> century**

Care 21 is a new programme aimed at driving up the quality of social care services in Scotland. Its main objective is to create better services for people, by seeking the best ideas and practice from Scotland, UK and abroad, in the public, private and voluntary sectors.

Website:

[http://80.75.66.189/care21/care21\\_display\\_home.jsp?pElementID=1&pContentID=3&p\\_applic=CCC&pMenuID=8&p\\_service=Content.show&](http://80.75.66.189/care21/care21_display_home.jsp?pElementID=1&pContentID=3&p_applic=CCC&pMenuID=8&p_service=Content.show&)

## Useful organisations continued

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### **The Care Commission**

The Scottish Commission for the Regulation of Care (The Care Commission) is a national organisation set up under the Regulation of Care (Scotland) Act 2001 to regulate and inspect Scottish care services.

Website: <http://www.carecommission.com/CareComm.Web/default.aspx>

### **Carers Scotland**

Carers Scotland is the Scottish national office of Carers UK and is the only carer-led organisation working for all carers.

Website: <http://www.carerscotland.org/Home>

### **Centre for Accessible Environments (CAE)**

The Centre for Accessible Environments (CAE) is an information provider and a forum for collaborative dialogue between providers and users on how the built environment can best be made or modified to achieve inclusion by design. They have undertaken considerable work within the health service.

Website: <http://www.cae.org.uk/>

### **Child Health Support Group**

The Child Health Support Group is an expert advisory group, established by the Scottish Executive in 2000 to bring together a wide range of professionals from across Scotland to co-ordinate and drive forward improvements in child health and the quality of child health services. Part of its role is to promote and develop good practice in the involvement of children and young people within the Health Service.

Website: <http://www.show.scot.nhs.uk/chsg/>

### **Children in Scotland**

Children in Scotland is the national agency for voluntary, statutory and professional organisations and individuals working with children and their families in Scotland.

Website: <http://www.childreninscotland.org.uk/>

### **Community Health Exchange (CHEX)**

The Community Health Exchange – CHEX – is part of the Community Development Foundation. It is funded by the NHS Health Scotland. CHEX's target groups are community health projects and community health initiatives across Scotland. It also works with practitioners, policy makers and managers from services in health boards, local authorities, housing agencies and voluntary organisations; essentially all those who have a focus or interest in promoting a community development approach to tackling health inequalities. This website is a useful resource for information and local community health developments.

Website: <http://www.scdc.org.uk/chex/home/about.htm>

### **Community Care Providers Scotland (CCPS)**

CCPS is the association of voluntary sector organisations providing care and support services in Scottish communities. Its membership comprises the majority of the leading national non-profit and

## Useful organisations continued

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charitable service providers in Scotland. CCPS exists to identify, represent, promote and protect the interests of its members, so that they can maximise the support they provide to the people who use their services.

Website: <http://www.ccpscotland.org/>

### **Connects: the Mental Health and Learning Disabilities Portal**

Connects is a worldwide, interactive website for the sharing of information by people interested in mental health problems and/or learning disabilities. They currently have 10,000 plus members.

Website: <http://www.connects.org.uk/index.cfm?js=1&dom=1>

### **Consultation and Involvement Trust Scotland**

Consultation and Involvement Trust Scotland helps people with health and social support needs, and their carers, to control and influence the services they use.

Email: [involve@citscotland.org.uk](mailto:involve@citscotland.org.uk)

### **Criminal Justice Social Work Development Centre for Scotland**

The Criminal Justice Social Work Development Centre for Scotland was established in 2001 to assist in the development and implementation of evidence based practice in Scotland.

Website: [http://www.cjsw.ac.uk/servlet/page?\\_pageid=51&\\_dad=portal30&\\_schema=PORTAL30](http://www.cjsw.ac.uk/servlet/page?_pageid=51&_dad=portal30&_schema=PORTAL30)

### **Dementia Services Development Centre**

The Dementia Services Development Centre at the University of Stirling, exists to extend and improve services for people with dementia and their carers in Scotland. All of their objectives are centred around this purpose.

Website: <http://www.dementia.stir.ac.uk/>

### **Disability Rights Commission – Scotland**

The Disability Rights Commission (DRC) is an independent organisation with the goal of “a society where all disabled people can participate fully as equal citizens”.

Website: <http://www.drc-gb.org/scotland/index.asp>

### **Down's Syndrome Scotland**

Down's Syndrome Scotland is based in Edinburgh. They work to improve the quality of life for everyone with Down's Syndrome in Scotland.

Website: <http://www.dsscotland.org.uk/>

### **Equal Opportunities Commission**

The Equal Opportunities Commission works to eliminate sex discrimination in the United Kingdom, including within the Health Service.

Website: <http://www.eoc.org.uk/>

## Useful organisations continued

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### **ENABLE**

ENABLE is the largest membership organisation for people with learning disabilities and their families in Scotland.

Website: <http://www.enable.org.uk/>

### **The Foundation for People with Learning Disabilities**

The Foundation for People with Learning Disabilities was established in 1998. A UK wide organization, it works with people and their families to ensure they can use effective services, play a fuller part in communities and society, and enjoy equal rights. It runs the Choice forum, an online discussion forum. The Foundation has excellent information. It has published a resource list and people with learning disabilities from ethnic minority communities.

Website: <http://www.learningdisabilities.org.uk>

### **Glasgow University Affiliated Programme**

Glasgow University Affiliated Programme is made up of a number of departments with interests in people with learning disabilities:

Website: <http://www.gla.ac.uk/>

Also see: <http://www.gla.ac.uk/departments/psychologicalmedicine/UAP%20in%20Learning%20Disabilities/Index%20Page%20for%20UAP%20in%20Learning%20Disabilities.htm>

### **Health Scotland**

Health Scotland is a new special health board created on 1 April 2003 by bringing together the Public Health Institute of Scotland (PHIS) and the Health Education Board for Scotland (HEBS). It provides a national focus for improving health and works with the Scottish Executive and other key partners to take action to improve health.

Website: <http://www.phis.org.uk/>

A summary version of the Learning Disability Health Needs Assessment can be found on their website at: <http://www.phis.org.uk/pdf.pl?file=pdf/LDSummary.pdf>

### **Inclusion Scotland**

Inclusion Scotland (IS) is a consortium of disability-led organisations and individual disabled people. It aims to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect our everyday lives as disabled people in Scotland.

Website: <http://www.inclusionscotland.org/>

### **The King's Fund**

The King's Fund is an independent charitable foundation whose goal is to improve health, especially in London. They have produced a wide range of resources on improving public and patient involvement, many of which are available free of charge.

Website: <http://www.kingsfund.org.uk/>

## Useful organisations continued

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### **Local Area Co-ordination**

The SCLD site which provides more information on Local Area Co-ordination and where to find the person closest to you.

Website: <http://uk.geocities.com/localareacoordination/>

### **Mainstreaming Equality**

The homepage of the Scottish Executive's Equality Strategy.

Website: <http://www.mainstreaming/default.aspxpageid=403&maincat=16&subcat=16>

### **Mencap**

Mencap is the UK's leading learning disability charity working with people with a learning disability and their families and carers. It seeks to promote equal rights, to campaign for greater opportunities and challenge attitudes and prejudice.

Website: <http://www.mencap.org.uk/>

### **Mental Welfare Commission for Scotland**

An independent organisation set up by Parliament, the Mental Welfare Commission has the responsibility of protecting the welfare of people with mental disorder (including learning disabilities and dementia) in Scotland. It has a duty to anyone with a mental disorder whether they are in hospital, in local authority, voluntary run or private accommodation or in their own homes. Their work includes visiting people in hospital and in the community, investigating cases of deficiency in care or treatment and providing information and advice.

Website: <http://www.mwcscot.org.uk/act.htm>

### **The National Centre for Social Research**

The National Centre for Social Research (NatCen) is the largest independent social research institute in Britain. It designs, carries out and analyses research studies in the fields of social and public policy - including extensive research among members of the public.

Website: <http://www.natcen.ac.uk/>

### **The National Autistic Society**

The National Autistic Society exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs.

Website: <http://www.nas.org.uk/>

### **The National Network for the Palliative Care of People with Learning Disabilities (NNPCPLD)**

The NNPCPLD was set up in November 1998. It was established by a small group of practitioners from either learning disability or palliative care services that were concerned that people with learning disabilities were not routinely accessing palliative care services when confronted with life threatening/limiting illnesses.

Website: [http://www.helpthehospices.org.uk/professional/dsp\\_professional.asp?ass=7](http://www.helpthehospices.org.uk/professional/dsp_professional.asp?ass=7)

## Useful organisations continued

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### **NHS Education for Scotland (NES)**

NHS Education for Scotland (NES) has the aim to promote best practice in the education and lifelong learning of all NHS staff and is the health service's very own training organisation, that exists to advance the knowledge and develop the skills of all NHS staff.

Website: <http://www.nes.scot.nhs.uk/>

### **NHSScotland Involving People**

The Involving People team are part of NHSScotland and are charged with promoting public involvement and patient focus within the Health Service. This website is part of the Scottish Executive Health Department's commitment to improving Public / Patient Focus and Quality. It seeks to act as a central resource providing information on training, new projects and initiatives, publications and resources, and information on the Involving People Network.

Website: <http://www.show.scot.nhs.uk/involvingpeople/>

### **NHS Quality Improvement Scotland**

The role of NHS Quality Improvement Scotland is to improve the quality of healthcare in Scotland. It does so by setting standards, monitoring performance, and providing advice, guidance and support to NHSScotland on effective clinical practice and service improvements.

Website: <http://www.nhshealthquality.org>

### **The National Resource Centre for Ethnic Minorities**

The National Resource Centre for Ethnic Minorities was set up by the Scottish Executive within NHS Health Scotland to support NHS Boards to meet their responsibilities and to deliver culturally competent services and promote race equality.

Website: <http://www.phis.org.uk/projects/default.asp?p=fd>

### **Norah Fry Research Centre**

The Centre was established in 1988 as part of the University of Bristol's Department of Mental Health. Its principal interests are the evaluation and development of services for people with learning difficulties. They have completed a research project on making information accessible to people with learning disabilities.

Website: <http://www.bris.ac.uk/Depts/NorahFry/>

### **One for Us**

This website is designed and managed by people with a learning disability. You will find information and stories about people who have a learning difficulty.

Website: <http://www.oneforus.com/>

### **PAMIS**

PAMIS provide services and support to parents and professionals for people with profound and multiple learning disabilities.

Website: <http://www.dundee.ac.uk/pamis/>

### **People First**

The national self-advocacy organisation, run by and for people with learning difficulties.

Website: <http://www.peoplefirst.org.uk/>

## Useful organisations continued

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### **The Princess Royal Trust for Carers**

The Princess Royal Trust for Carers website aims to offer useful information and support for all unpaid carers throughout the UK.

Website: <http://www.carers.org>

### **The Quality Network**

The Quality Network works with people to monitor outcomes. It is an initiative of the British Institute of Learning Disabilities and the National Development Team.

Website: <http://www.qualitynetwork.org.uk>

### **Scotland's Health on the Web (SHOW)**

The SHOW service is provided by a team of people based within the Information and Statistics Division of NHS Scotland. In addition to the SHOW team, the contributing websites on SHOW are provided by the organisations themselves and a dedicated army of NHS Scotland staff.

Website: <http://www.show.scot.nhs.uk>

### **Scottish Accessible Information Forum (SAIF)**

SAIF's remit is to develop and promote quality standards in information provision to disabled people and carers; to represent and promote the interests of disabled people in having access to information services; to promote communication between national and local information providers; to advise the Scottish Executive on policy relating to accessible information and to improve disabled people's access to information.

Website: <http://www.saifscotland.org.uk/>

### **Scottish Consortium for Learning Disability (SCLD)**

SCLD was established in 2001 to offer training, advice and support to bring about the changes recommended in 'The same as you?'. The Scottish Consortium for Learning Disability (SCLD) can help you to involve people with learning disabilities and family carers. We also provide training for staff and local groups. It is a partnership of 13 organisations and works across Scotland, supporting change through training, consultancy and providing evidence based information. For more information contact:

Andy Miller, Policy and Practice Development Manager. Email: [andy.m@sclld.co.uk](mailto:andy.m@sclld.co.uk)

Website: <http://www.sclld.org.uk/>

### **Scottish Executive – Supporting People Unit**

The Scottish Executive Supporting People website provides information about how Supporting People is being implemented in Scotland.

Website: <http://www.scotland.gov.uk/housing/supportingpeople/default.asp>

### **Scottish Independent Advocacy Association**

The SIAA provides advice, support and information to local advocacy organisations.

Website: <http://members.lycos.co.uk/powerfulpartnerships/siaa/pages/>



## Useful organisations continued

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### **Scottish Institute for Excellence in Social Work Education (SIESWE)**

Established in 2003, a partnership of 9 universities offering social work programmes.

Website: <http://www.sieswe.org>

### **Scottish Institute for Residential Childcare (SIRCC)**

A partnership organisation which offers training to improve the quality of care that young people receive in residential care

Website: <http://www.sircc.strath.ac.uk>

### **Scottish Intercollegiate Guidelines Network**

The Scottish Intercollegiate Guidelines Network (SIGN) was formed in 1993. Its objective is to improve the quality of health care for patients in Scotland by reducing variation in practice and outcome, through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence

Website: <http://www.sign.ac.uk/>

### **Scottish Partnership for Palliative Care**

The Scottish Partnership for Palliative Care is a national umbrella body which is of direct benefit to patients and carers. It contributes to national thinking and policy in relation to palliative care, and promotes improvements in service delivery at local level.

Website: <http://www.palliativecarescotland.org.uk/>

### **The Scottish School of Primary Care**

The Scottish School of Primary Care is the national organisation promoting research and increasing capacity for research in primary care across Scotland. Funded by the Scottish Executive Health Department, the Scottish School is part of NHS Education for Scotland.

Website: <http://www.show.scot.nhs.uk/sspc/>

### **Scottish Social Services Council**

The Scottish Social Services Council is responsible for raising standards in the Scottish social service workforce. Their vision is a competent, confident workforce, capable of delivering high quality services that have the confidence of the public, and those who use services and their carers. They seek to put service users and carers at the centre of everything they do.

Website: <http://www.sssc.uk.com>

### **The Scottish Society for Autism**

The Scottish Society for Autism works together with persons with Autism Spectrum Disorder (ASD), their families, carers, and other organizations, agencies, and individuals in Scotland to improve educational, social and care services, increase public awareness and influence policy.

Website: <http://www.autism-in-scotland.org.uk/>

### **Scottish Training on Drugs and Alcohol (STRADA)**

A partnership to improve the skills of professional staff and ensure that practice is evidence-based.

Website: <http://www.projectstrada.org/website/index.html>

### **Sense Scotland**

Sense Scotland is a leader in the field of communication and innovative support services for people



## Useful organisations continued

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who are marginalised because of challenging behavior, health care issues and the complexity of their support needs.

Website: <http://www.sensescotland.org.uk/>

### **Sharing Value**

A directory which provides examples of valued services commended by disabled children and their families.

Website: <http://www.sharingvalue.co.uk/>

### **Social Care Institute for Excellence**

SCIE promotes good practice in social care. It does this by reviewing knowledge to find out what works best, and sharing that knowledge with all kinds of people involved in social care.

Website: <http://www.scie.org.uk/>

### **Social Work Inspection Agency**

The purpose of the Inspectorate is to work with others to continually improve social work services, so that they meet the needs of the public; and the public has confidence in them

Website: <http://www.scotland.gov.uk/about/cs/UNASS/00015838/home.aspx>

### **The University of Dundee**

The White Top Research Unit conducts multidisciplinary research in the area of profound and multiple disability.

Website: <http://www.dundee.ac.uk/>

### **The University of St Andrews**

The University of St Andrews runs accredited open learning and short course programmes for staff working with people with learning disabilities

Website: <http://www.st-andrews.ac.uk/>

### **Values into Action**

VIA is a UK-wide campaigning organisation and registered charity which works to promote the right of people with learning difficulties to become citizens with full access to the opportunities of ordinary community life; and to promote the development of policies, services and public attitudes which will achieve that aim human beings are respected.

Website: <http://www.viauk.org/>

### **Valuing People Support Team**

Valuing People is the government's plan for making the lives of people with learning disabilities and their families better. You can find out about these things on this website: what Valuing People is about; papers and links to help local people make Valuing People happen; what is happening across the country and who the Valuing People Support Team are and what we do.

Website: <http://www.valuingpeople.gov.uk/index.htm>

## Organisations specialising in communication

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### Specialised Communication Centres

In Scotland, there are a number of specialised centres and services that provide advice and information on special communication methods, low and high tech, and in some cases assessment and loans of communication aids for trial, and training. There are local Centres for Edinburgh & the Lothians, Fife and Aberdeen City. Otherwise, there are two national centres with a Scotland-wide remit; SCTCI (adults and children) and CALL Centre (mainly children); either of these may be contacted as a first point of information, rather than listing each centre separately.

### Communication Aids for Language and Learning (CALL) Centre

Patersons Land  
Holyrood Road  
Edinburgh  
EH8 8AQ;  
Tel: 0131 651 6236  
Email: [call.centre@ed.ac.uk](mailto:call.centre@ed.ac.uk)  
Website: <http://www.callcentrescotland.org.uk>

### Scottish Centre of Technology for Communication Impaired (SCTCI)

WESTMARC, Southern General Hospital, 1345 Govan Road, Glasgow G51 4TF;  
Tel: 0141 201 2619  
Email: [sctci@sgh.scot.nhs.uk](mailto:sctci@sgh.scot.nhs.uk)

### AAC Research Unit, Dept. of Psychology, University of Stirling

Development work and training on the Talking Mats technique for consulting communication impaired people for their views, and information about resources available.

Website: <http://www.aacscotland.com>

### ACE Centre Advisory Trust

The ACE Centres website provide specialised information on communication aid technology and many useful downloadable resources.

Website: <http://www.ace-centre.org.uk>

### Acting up

Acting Up, part of Matchbox TheatreTrust, has been working with people with communication difficulties since 1987, and has pioneered multimedia communications' training with services in the voluntary and statutory sectors.

Website: <http://www.acting-up.org.uk/>

### Afasic

Afasic is a UK charity representing children and young adults with speech and language impairments and providing information and advice for a list of publications.

Afasic Scotland Email: [afasicscotland@btopenworld.com](mailto:afasicscotland@btopenworld.com)

Website: <http://www.afasic.org.uk>

### Augmentative Communication in Practice: Scotland

A Scottish group that runs an annual study day on aspects of augmentative and alternative communication, and publishes papers from these study days. See the CALL Centre website (over)

## Organisations specialising in communication

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which gives information about events and publications, and downloadable materials, specifically the book 'Augmentative communication in practice: An introduction'.

Website: [http://callcentre.education.ed.ac.uk/SCN/Intro\\_SCA/intro\\_sca.html](http://callcentre.education.ed.ac.uk/SCN/Intro_SCA/intro_sca.html)

### **Communication Aids for Language and Learning (CALL) Centre**

A centre with a national Scotland-wide remit to provide information and advice, assessments, loans and technical services, and research and development. The web site provides information, and many useful links and useful downloadable resources including several whole books e.g 'Supportive Writing Technology'.

Website: <http://callcentrescotland.org.uk>

Resources Section:

[http://callcentre.education.ed.ac.uk/Useful\\_Links/Allan\\_ULA/allan\\_ula.html](http://callcentre.education.ed.ac.uk/Useful_Links/Allan_ULA/allan_ula.html)

### **Communication Matters**

This is a national charitable organization concerned with augmentative and alternative communication. It provides free information leaflets on AAC and runs a national conference annually.

Website: <http://www.communicationmatters.org.uk/>

### **Pyramid Educational Consultants UK Ltd.**

The organisation that provides information and training in PECS (the Picture Exchange Communication System) used mainly with people with autism.

Website: <http://www.pecs.org.uk>

### **The Trans-active Project**

The Trans-active Project is for teenagers with and without learning disabilities working together, it uses multimedia to explore and communicate and uses and gives support making future plans.

Website: <http://www.trans-active.org.uk>

### **Widgit Software**

Widgit Software is the longest running Special Educational Needs software company in the UK. Its products are designed to develop literacy using pictures, symbols and words, particularly for learners who have a measure of difficulty in developing traditional orthographic skills. It has information on 'How Symbols Help'.

Website: <http://www.widgit.com/index.htm>

### **Education**

In most local authorities, there is a person with responsibility for information communication technology (ICT) and Additional Support for Learning (ASL) in education, and they are all part of a national network known as ICT for Support for Learning in Scotland (ICTSLS). To see the full list and contact numbers, email addresses etc look at this webpage:

[http://callcentre.education.ed.ac.uk/Useful\\_Links/Useful\\_Geo\\_Links/Scotland\\_ULA/ICTSLS\\_ULB/ictsls\\_ulb.html](http://callcentre.education.ed.ac.uk/Useful_Links/Useful_Geo_Links/Scotland_ULA/ICTSLS_ULB/ictsls_ulb.html)

## Useful health resources for people with learning disabilities

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### Books Beyond Words

This series of 30 counselling picture books for people with learning disabilities is edited by Shelia Hollins. They can be used by anyone who understands pictures better than words. Supporting text and guidelines are given at the back of the book. Titles include:

- A New Home in the Community
- Bob Tells All
- Falling in Love
- Feeling Blue
- Food...Fun, Health and Safe
- George Gets Smart
- Getting on with Cancer
- Getting on with Epilepsy
- Going into Hospital
- Going to the Doctor
- Going to Out-Patients
- Hug Me Touch Me
- Jenny Speaks Out
- Keeping Healthy 'Down Below'
- Looking After my Balls
- Looking After my Breasts
- Making Friends
- Michelle Finds a Voice
- Peter's New Home
- Speaking Up For Myself
- I Can Get Through It
- Susan's Growing Up
- When Dad Died
- When Mum Died
- When Somebody Dies

The books cost £10 each with a 10% discount for 10 or more books. They are available from:

The Royal College of Psychiatrists  
17 Belgrave Square  
London  
SW1X 8PG

Tel: 020 72 35 2351 ext. 146

Website: <http://www.rcpsych.ac.uk/publications/bbw>

## Useful health resources for people with learning disabilities

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### British Institute for Learning Disabilities (BILD)

BILD have produced a series of 12 illustrated booklets in the series *Your Good Health*. Titles include:

- Pregnancy and Children
- Epilepsy
- Exercise
- Breathe Easy
- Eating and Drinking
- Alcohol and Smoking
- Looking after your Teeth
- Seeing and Hearing
- Sex
- If you are Ill
- Using Medicine Safely
- Coping with Stress
- Getting Older- Feeling Good

They cost £60 for the set or £5.50 each.

BILD have three booklets on understanding death and dying, written by Fiona Cathcart, are designed for children and adults. They can be used if a friend is diagnosed as having a terminal illness or to help come to terms with bereavement.

- Book 1: Your Feelings (illustrated)
- Book 2: A Guide for Family and Friends
- Book 3: A Guide for Carers and Other Professionals

They are available from:

BILD Book Sources  
32 Finlas Street  
Cowlairs Estate  
Glasgow  
G22 5DU

Tel: 08 702 402 182

## Useful health resources for people with learning disabilities

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### Down's Syndrome Scotland

Down's Syndrome Scotland have written some illustrated booklets for people with learning disabilities including:

- Keeping Well
- Lets Talk about Death
- Lets Talk about Getting Older
- Lets Talk about Puberty
- Sibling- Growing Up with your brother or sister with Down's Syndrome

These are available from:

Down's Syndrome Scotland  
58-160 Balgreen Road  
Edinburgh  
EH11 3AU

Tel: 0131 313 4225

Email: [info@dsscotland.org.uk](mailto:info@dsscotland.org.uk)

Website: <http://www.dsscotland.org.uk>

### The Elfrida Society

The Elfrida Society and women with learning difficulties have worked together to produce some illustrated booklets on womens health:

- Cathy has Thrush
- Hysterectomy- is it right for you?
- Hysterectomy- having the operation
- Period problems- what you can do.

Each booklet is free to individual women with learning difficulties.

These are available from the website: <http://www.womenshealthlondon.org.uk>

Tel: 020 7251 6333

There are also booklets in the Access to Health series:

- Having a blood test
- Having a CT Scan
- Having an EEG
- Having an MRI Scan

These are £2 each.

There is a series of 15 booklets on mental health medication. These are £1 each or £14 for the set.

There is also a series of Healthy Living booklets:

- Food
- Keeping Clean
- Safety in the Home
- Epilepsy
- Coming for a Drink?

Available from:

## Useful health resources for people with learning disabilities

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The Elfrida Society  
Tom Blyth Centre  
34 Islington Park Road  
London  
N1 1PX

Tel: 020 7359 7443  
Email: [elfrida@elfrida.com](mailto:elfrida@elfrida.com)

Website: <http://www.elfrida.com/publ.html>

### Family Planning Association

The Family Planning Association have booklets on:

- Talking Together about Growing Up
- Talking Together about Sex and Relationships (for age 13+)
- Sexuality and Learning Disability

Family Planning Association Direct  
The Whitbread Centre  
Rhymney  
Gwent  
NP22 5XD

Tel: 01685 846 678

Website: <http://www.fpa.org.uk/about/pubs/index.htm>

### FAIR Multimedia

FAIR Multimedia have produced health information for people with learning disabilities. Booklets with full colour illustrations include:

- Guide to Checking your Breasts
- Guide to Examining your Testicles
- Guide to Having a Health Heart
- Guide to a Health Mouth (also available in Chinese)
- Men's Guide to Keeping Clean
- Women's Guide to Keeping Clean
- Living with Cancer - What is cancer?

These are available for free from your local health promotion library.

1-50 copies: 50p each  
51-100 copies: 40p each  
100+ copies: 35p each

Multimedia packs are designed to complement the leaflet and include a CD ROM plus leaflet. For use with Windows.

- Guide to checking your breasts.
- Guide to examining your testicles

Cost £3.50 each

FAIR Multimedia  
25-27 West Nicolson Street

## Useful health resources for people with learning disabilities

Edinburgh  
EH8 9DB

Tel: 0131 662 1962

E-mail: [multimedia@fairadvice.org.uk](mailto:multimedia@fairadvice.org.uk).

Website: <http://www.fairadvice.org.uk/>

### Learning Disabilities Federation in North Tyneside

#### Can I make an appointment please?

An innovative communication toolkit for people with learning disabilities, primary care staff and others. £70 includes postage and packaging. Available from:

Alison Chalmers  
Learning Disabilities Federation  
83 Howard Street  
North Shields  
NE30 1AF

Tel: 0191 200 1013

### PAMIS (Promoting a More Inclusive Society)

#### Medication Record

PAMIS have developed a Medication Record folder for carers of children and adults with complex health needs. This is for the carer to use and will be particularly useful when visiting the doctor.

Available from:

Scottish Consortium for Learning Disability Adelphi Centre Room 16 12 Commercial Road Glasgow G5 0PQ  Tel: 0141 418 5420 Email: <a href="mailto:administrator@sclld.co.uk">administrator@sclld.co.uk</a> Website: <a href="http://www.sclld.org.uk">http://www.sclld.org.uk</a>	PAMIS Springfield House 15/16 Springfield University of Dundee Dundee DD1 4JE  Tel: 01382 345 154 Email: <a href="mailto:pamis@dundee.ac.uk">pamis@dundee.ac.uk</a> Website: <a href="http://www.dundee.ac.uk/pamis">http://www.dundee.ac.uk/pamis</a>
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### Real Lives: Real Stories

PAMIS has produced 50 personalised multi-sensory stories in collaboration with parents, carers and teachers. Each story is relevant to a particular child or young person with profound and multiple learning disabilities.

Copies of the stories are available from the PAMIS multi-sensory story library. PAMIS is a partner in the SCLD library.

See contact details above



## Useful health resources for people with learning disabilities

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### Pavilion Publishing

#### **Becoming a Woman.** (1999) E Cooper.

A teaching pack and menstruation for young women with learning disabilities.

Becoming A Woman is aimed at educating women with learning disabilities about this important life event. This resource explains what will, and may happen to them when they have a period, exploring the physical realities of dealing with a period and the possible emotional effects that can occur within a menstrual cycle.

#### **Smoking Awareness Pack.** (1999)

A light-hearted visual resource to use with people with learning difficulties and young adults, this colourful teaching pack is designed to assist facilitators in describing the effects of smoking and methods to help people stop smoking. The handbook is structured into 22 sessions each incorporating facilitator guidance notes, discussion pointers, briefing notes and statistics.

Available from their website:

<http://www.pavpub.com/pavpub/home/index.asp>

### Scottish Consortium for Learning Disability

#### **Our Health Matters!**

A summary of the Health Needs Assessment Report for people with learning disabilities in Scotland. Funded by NHS Health Scotland. Also available from your local health promotion library.

#### **Having Our Say!**

A video/DVD about the CAN network which builds the capacity of individuals and groups to become trainees and consultants with SCLD shows the confidence and achievements of people with learning disabilities engaging in public life locally and nationally.

#### **The Health Challenge Bulletin** (Learning Disability Week 2004)

A bulletin giving some examples of good worker happening to improve the health of people with learning disabilities in Scotland, first hand experiences as well as a list of information people may find useful.

#### **Top Tips for Health Professionals**

A postcard you can give to your GP or other health professionals.

#### **How to give Information about Medicines**

Values into Action (VIA) have written a good practice guide for the Scottish Consortium for Learning Disability on giving information about medicine to people with learning disabilities.

Available from:

Scottish Consortium for Learning Disability  
Adelphi Centre Room 16  
12 Commercial Road  
Glasgow, G5 0PQ.

Tel: 0141 418 5420

Email: [administrator@sclld.co.uk](mailto:administrator@sclld.co.uk)

Website: <http://www.sclld.org.uk>

## Useful health resources for people with learning disabilities

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### **Improving the Health of People with Learning Disabilities**

An easy to read version of the NHS QIS Learning Disability Quality Indicators.

Also available from:

NHS QIS

Elliott House

8-10 Hillside Crescent

Edinburgh, EH7 5EA.

Tel: 0131 623 4300

Website: <http://www.nhshealthquality.org>

Email: [learningdisabilities.federation@virgin.net](mailto:learningdisabilities.federation@virgin.net)

### **Speak Up Self Advocacy**

#### **Coping with Death**

This is a short video resource which explains what happens when someone dies. It shows burial and cremation. It shows people talking about their feelings and thoughts and what some people do to remember friends and family who have died.

Tel: 01709 710 199

Email: [committee@speakup.org.uk](mailto:committee@speakup.org.uk)

## Evaluation form

# It's Our Health Service!

## Evaluation Form

Please help us to improve this pack by giving us feedback. Copy this form to everyone who gets the pack.

How useful were the different types of material in the pack?

Useful      Not Useful      Didn't Use

Guidance and top tips

Sample Questionnaires etc

CD


Are there other types of material it would be helpful to have?

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Did you change anything about the way you involve people with learning disabilities and family carers as a result of using this pack?

YES/NO

Please tell us more

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## Evaluation form continued

Did you use any of the guidance/ top tips in this pack and what did you think?

	Useful	Not Useful	Didn't Use
Overview of guide			
Strategic Framework			
Involving people			
Frequently asked questions			
Communication			
Top tips for consulting people			
Top tips for consulting children			
Top tips for consulting family carers			
Making it real			
An example			
Collecting and reviewing evidence			
Planning an Information Strategy			
Index to the Quality Indicators			
Obtaining views methods that work			

Are there any other topics you would like information on?

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Did you use any sample materials in the pack and what did you think?

	Useful	Not Useful	Didn't Use
CALL Centre Communication Behaviour Checklist			
CALL Centre Communication Behaviour Checklist 2			
Questionnaire to family carers			
Key questions for people with learning disabilities			
Interview with long-stay hospital resident			
Group discussion with planning group representatives			
Focus group on accessible information			
Sample format for story gathering on primary care services			
The healthy tree game			
"I do stuff!"			
Analysing stories and accounts			
Case Study			

If you have specific comments on any of these we would really like to hear from you.

## Evaluation form continued

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Are there other materials you would find helpful?

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Did you use any of the resources for people with learning disabilities and family carers and what did you think?

	Useful	Not Useful	Didn't Use
Letter to advocacy groups and others			
Guide to indicators for people with learning disabilities			
Guide for Parents and Family Carers			
Other...			

Have you developed any materials/resources that you would like to share with other people? Please let us see them.

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Do you know of other resources that you think others would find helpful? Please tell us about them.

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Tell us two things that worked best for you in involving people with learning disabilities and family carers.

1.....

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2.....

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## Evaluation form continued

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Tell us two things that didn't go so well and you will learn from.

1.....

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2.....

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What single thing helped most in involving people with learning disabilities and family carers?

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Are you from:

An NHS Board  
A Local Authority  
A Provider  
An Advocacy Group  
A Carer Group  
Other...


Thank you.

Please return this form to:

Learning Disability Team

NHS Quality Improvement Scotland  
Freepost SC05432  
Edinburgh  
EH7 0BR

Tel: 0131 623 4300

Website: <http://www.nhshealthquality.org>